

CHAT 21



Journal About & For The New Zealand Down Syndrome Community

ISSUE 81, Autumn 2020

ISSN 11776323



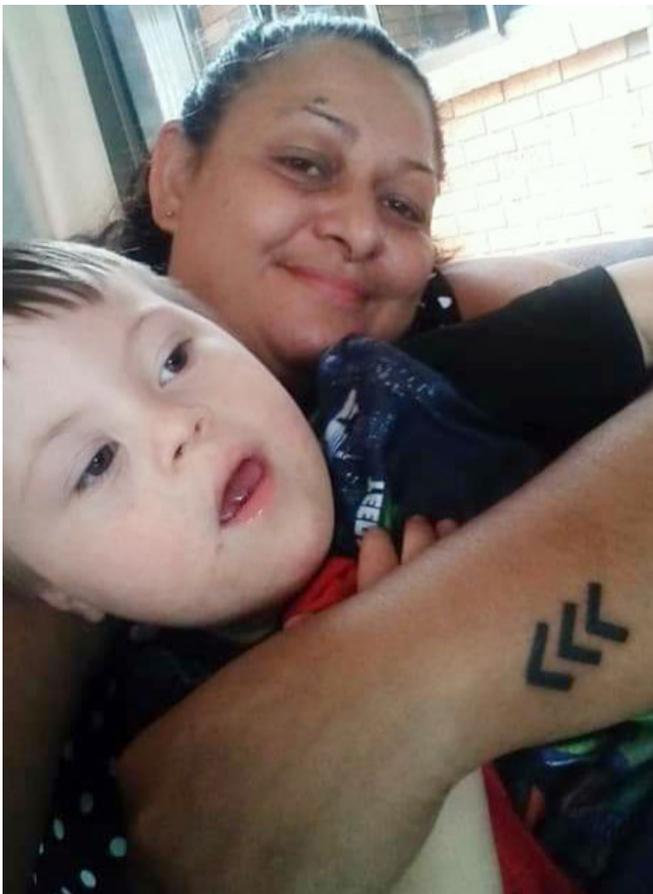
Our People



Phoenix Fowler on the move



Dain Whiting in the fast lane



Julie Fowler and her son



Chand family

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This issue of CHAT 21 was made possible with donations from Southern Stars.

From the Editor

The Covid 19 virus is touching all aspects of New Zealand society and unfortunately World Down Syndrome Day was heavily affected.

All the great preparation work by volunteers around the country, sadly did not get rewarded with a great event.

This edition of CHAT 21 would normally have been mainly dedicated to WDSO, but instead we are offering you a host of wonderful stories from around the country in which we celebrate people with Down syndrome and their families, even without WDSO.

In this edition you will find a report from the special Tattoo Bonanza organised by Dawn Goddard in which over 40 people got the special Lucky Ones tattoo on WDSO.

Actors with Down syndrome are appearing more and more on the big screen and in theatre so we have a special feature on three special young women who are not afraid to strut their stuff in front of an audience or camera.

In Down Write Brilliant we are featuring Leroy and his tramping exploits, Emily and her drumming adventures, Luka becoming a Youtube sensation, Veshun and Mohit talking their jobs and the Palmerston North locals explaining why the Creative journeys hub is so important in their lives.

This journal also features a regional focus story on Wellington DSA, a health feature on oral health, a Champion Centre story about parent networks and the Special Olympics reporting from their young athletes programme.

WDSO may not have been what we had all hoped, but I hope you will still find plenty to read and to enjoy in this autumn edition of CHAT 21.

Again, I want to thank all the wonderful people around the country for contributing with ideas, stories and photos as we would not be able to put out a magazine without your help.

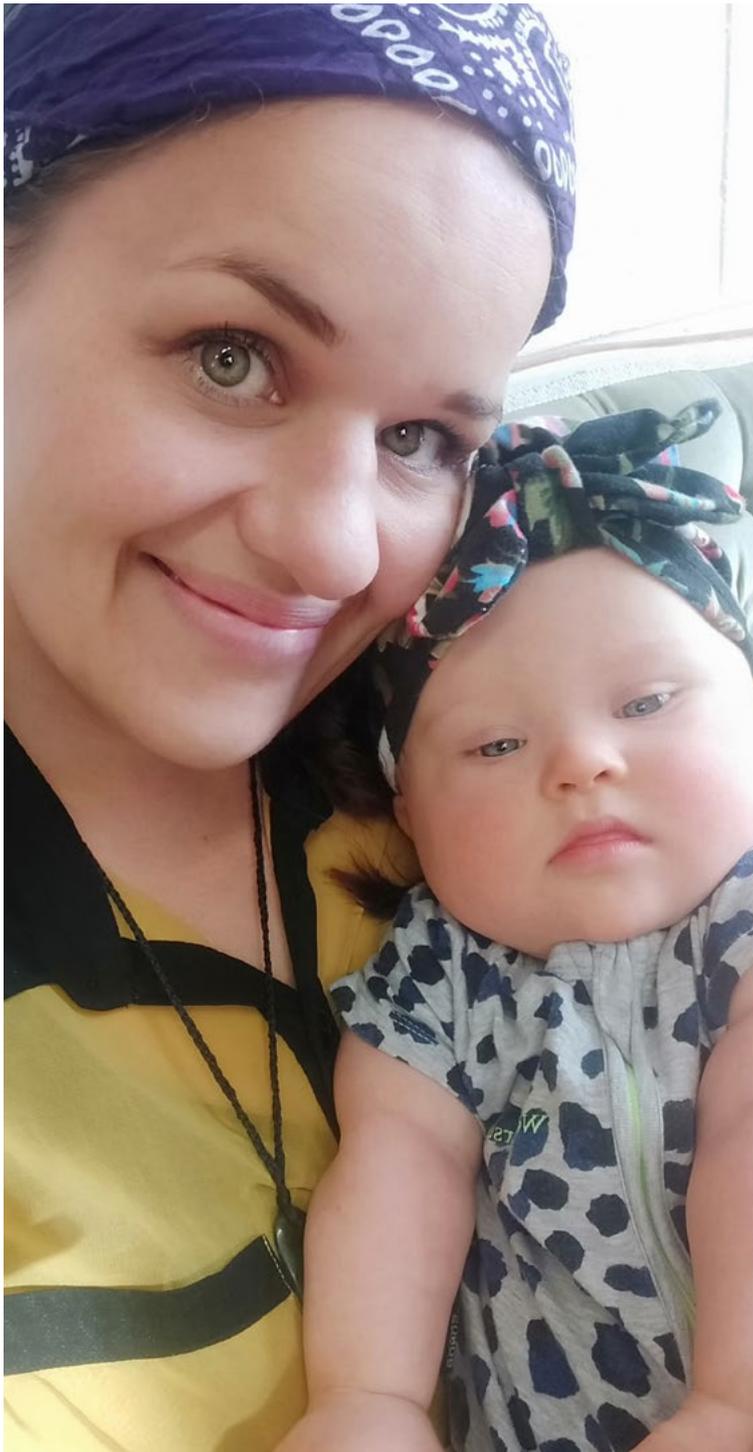
Please keep those coming and email me on editor@nzdsa.org.nz if you have any great stories you want to share.

Coen Lammers
Editor
editor@nzdsa.org.nz

Disclaimer: Through the quarterly Journal, the New Zealand Down Syndrome Association will attempt to report items of interest relating to Down syndrome. The NZDSA does not promote or recommend any therapy, treatment, agency, product, political position, religion or advice. The opinions expressed in CHAT 21 are not necessarily those of the NZDSA. The editor reserves the right to make corrections to materials submitted for publication. All photos sent in to the journal become the property of the NZDSA and can be used in other NZDSA publications.

'THE LUCKY FEW' TATTOO BONANZA

By Diane Burnett



Dawn Goddard and her daughter Paige



Matching tattoos for WDS



Damien Goddard



Cimara Lima and her son Eric



Ang Slater and tattoo artist Aaron van den Berg from 2 Sparrows Tattoo



Leonie Gillespie

To celebrate her beautiful baby girl Paige and World Down Syndrome Day 2020, Dawn Goddard had an inky idea.

Dawn wanted to get as many people as she can to get the world-renowned ‘the lucky few’ tattoo on 21st March, World Down Syndrome Day 2020. Dozens of people from across country from the New Zealand Group for Parents of Children with Down Syndrome Facebook group showed an interest, so Dawn contacted and organised quotes from a few tattoo studios.

Aaron V, co-owner of the family-owned private tattoo studio 2 Sparrows Tattoo in Pakuranga kindly offered to donate his time for free and charge only \$50 per ‘the lucky few’ tattoo to cover the cost of the materials required.

“The minimum cost for most tattoos nowadays is \$150 plus, so this is amazing,” said Dawn who was overwhelmed by the response.

Not only did 33 people show up in Pakuranga, but another 17 got their tattoo done in Te Awamutu and 21 others got the three arrows tattooed in Masterton, Tauranga, Whangarei, Wairarapa and elsewhere in Auckland.

One tattoo artist donated \$40 of every tattoo to raise hundreds of dollars for the Upside Down Trust.

Dawn, a photographer, also photographed the event and hoped the event to raise awareness of Down syndrome for World Down Syndrome Day 2020.

The original idea and design started in the United States where Mica May, a designer, had an idea to celebrate being a parent of a child with Down syndrome by designing a special tattoo for #theluckyfew.

She shared her idea with several other mums at their first gathering, having previously only met online. Their connection was immediate, and they discussed getting matching tattoos to acknowledge their bond.

At that point Mica spoke up and told them about the reoccurring dream she’d been having for a long time. In the dream, she wakes up with three black arrows on her arm – always the same design and always the same placement. As she described the design from her dreams, tears started rolling down the faces of the other mums, and everyone said “Yes! This is our design”.

The three arrows are the perfect symbol for parents of children with Down syndrome, because the number three is representative of the three 21st chromosomes that result in Down syndrome and the arrows represent how the parents of these special children rise up and move forward. “We rise the highest after we’ve been pulled back and stretched – sometimes even more than we think we can bear,” said Mica May.

The group tested the design on themselves that evening using a pen and decided to all get the tattoo the next day. But what started as a bonding moment for a small group of friends has grown to include hundreds of other parents from all over the world.

Last year, in Newquay in the UK, thirty parents joined the global campaign to raise awareness of people with Down syndrome. Each got ‘the lucky few’ tattoo to show how proud they are of their children and siblings with Down syndrome, and a person with Down syndrome also got the tattoo along with her mother and sister.

Dawn contacted one of the organisers of this event and got the details for the original designer, Mica May, who she contacted. “She has given us her blessing to use the design,” said an excited Dawn.



NORTHLAND GOES VIRTUAL FOR WDS D

By Jo Morrison

Due to concerns about the Coronavirus the Northland Down Syndrome Support Group had to take the hard decision to cancel our 'Lots of Rocks' Walk around the Hatea Loop in Whangarei, and instead to take our community celebrations online.

From Ahipara in the Far North to Ruakaka and further south, families posted photos of their WDS D2020 celebrations on our Facebook group. Event Organisers, Kathryn Sadgrove and Jo Morrison, said, "it was disappointing for us to cancel an event that brings so many people with Down syndrome, their families and their friends together for our global day of celebration.

"We were expecting around 250 participants from across the whole Northland region but we felt we had to play our part in protecting the community."

The local Northland business community has been very supportive and the group was able to use items originally donated as prizes, instead for an online silent auction. This means the support group was still able to carry out fundraising to support the work in Northland with whānau and schools.

The painted rocks that are usually hidden around the Hatea Loop during the walk will not go to waste. The children of Kamo Primary School and Onerahi Primary School who painted the rocks in colours of purple, orange and white, have taken them home and hidden them around the Whangarei District and beyond over the weekend. Anyone who finds one of these rocks is encouraged to post a photo of themselves to the charity's Facebook Group page and may even win a prize!

Kathryn and Jo confirmed that the 'Lots of Rocks' Walk event will be back on again next year.

"We are going to have great fun together online this year, but we do aim to be back and walking the Hatea Loop again next year for World Down Syndrome Day 2021."

MESSAGE OF INCLUSION & DIVERSITY LOUD AND CLEAR

By Zandra Vaccarino
National Executive Officer NZDSA

If you recently watched *The Project*, you may have seen the interview with Cherri Henry, the author of “We Can Make a Life”. Cherri is the sister of Rufus Henry, a young man with Down syndrome.

In the interview she said that while society is collectively starting to understand the importance of diversity and how it benefits each of us, she feels that it hasn’t fully extended to include disabled people as it should.

What resonated for me is that she feels part of the solution is about increasing visibility.

I believe greater visibility challenges stereotypical thinking and creates awareness. This provides more opportunity for true community participation which then leads to greater recognition that people with Down syndrome do contribute to society. And that will increase acknowledgement for equity, so that all people with Down syndrome can enjoy full citizenship rights like all New Zealanders.

I think that World Down Syndrome Day is an important vehicle that creates opportunities to ensure greater visibility of people with Down syndrome in the wider community, and of course it does provide the Down syndrome community with an occasion to gather and celebrate.

This year the NZDSA increased visibility of Down syndrome by launching the #We Decide digital



The star Lily Harper and Zandra

story to mark World Down Syndrome Day. During the filming of #We Decide, what struck me again was the vast range of talents, interests, accomplishments and skills of the individuals featured.

Each person’s story was so unique and it made me smile as it truly dispels the myths that people with Down syndrome are the same.

I hope you enjoy watching the #We Decide digital story. A special thank you to all involved in this project.

I know that around the country we all celebrated World Down Syndrome Day in diverse ways and you can read all about these unique events in this edition of CHAT 21.

I attended the celebrations in Palmerston North which included the launch of the #We Decide digital story. We viewed the extended version of #We Decide, which you can access on the NZDSA Facebook page.



Jesse Williams was one of the young adults featuring in the #WeDecide video to talk his work at the Lido Pool in Palmerston North.

PALMERSTON NORTH STARS IN WDSD VIDEO MESSAGE

By Coen Lammers

The Down syndrome community in Palmerston North was buzzing with excitement when several of them were asked to take part in a film shoot for the 2020 World Down Syndrome Day video message.

Director Dean Easterbrook and camera operator Bruce Nixon bounced around the city to cover numerous venues to interview adults with Down syndrome about their lives and to help deliver the global message “We Decide”.

The 2020 video message hopes to raise awareness about Down syndrome but specifically wants to remind the community that people with Down syndrome can and want to make their own decisions.

Dean and Bruce spoke to Vincenzo and Rachal Vaccarino about their married life, filmed Jesse Williams at his work place at the Lido Pool and then visited the Design School where Robyn Chok is completing a design course.

The crew then moved to the wonderful Creative Journeys hub where people with disabilities are encouraged to explore their artistic talents or just

hang out. First Nicholas Wales delivered his part of the script to camera before the crew filmed Georgia Garrett, who was supported by her choir Six To 60 who had all taken time out from work to watch Georgia’s interview.

When the heavens opened, the filming was forced inside and the director convinced the choir to deliver an impromptu performance of Elton John’s classic “I’m still standing” and it was clear to see how this group had fully embraced Georgia in their midst.

Next stop was the globe theatre where Lily Harper delivered an acting master class to camera. Lily was the lead actress in the play Up Down Girl at the same theatre and was clearly not intimidated by the spotlight.

The crew then moved to Hamish MacNeill bakery to film him at work in his new micro-business, before heading to the home purchased by Jessica Williams and Alec Cole, who have invited Lily as a flatmate.

The different settings in the video hopes to provide a compelling showcase of the variety and quality of activities people with Down syndrome are involved in and how they are all following their own passions.

In Auckland, the film makers also filmed Emma Sykes and Abigail Knight to provide the finishing touches for the video.

Disability Rights Commissioner Paula Tesoriero kindly agreed to support the project and provided the introduction to the video in which she describes how vital it is for all of us, inside and outside the Down syndrome community, to enable people with a disability to make their own choices.





Sam Stevens performing in the stage version of I am Sam



Sam Stevens

THEY CALL ME SAM

By Coen Lammers

They Call Me Sam aims to change perspective on disability

Jolt Dance in Christchurch has teamed up with Belmont Productions to create the short film “The Call Me Sam” to offer a different perspective on disability, focusing on the individual rather than the diagnosis.

The short film looks at the life of Sam Stevens, a Jolt dancer with Down syndrome.

The film grew out of a performance created by Jolt Youth in 2017 called “I am Sam” which was created in response to new pre-natal testing for Down Syndrome. In countries like Iceland, this testing has resulted in 100% abortion rates for babies with Down Syndrome.

“It is wonderful people can have choice, but the problem is the culture which is still really negative

about disability,” says Lyn Cotton, the Jolt artistic director.

“Through Sam’s life we were trying to ask those really big questions like ‘what does it mean to human?’”

The original show “I am Sam used dance, theatre and film, to portray who Sam is _from his birth and early life to the present day. Within that story we see Sam as an individual, not just as a person with Down syndrome.

The film They Call Me Sam uses dance scenes and rehearsals from that original production, as well as behind the scenes footage and interviews with Sam’s parents, other parents and performers.

“These dancers come through a society that has very low expectations, so we have to fight that,” says Cotton, who had hoped to first show the film in London this May.

Jolt Dance had been invited as special guests to the 40th anniversary of Amici Dance, one of the longest running inclusive dance companies, but due to the Covid 19 virus, these celebrations have been delayed. Jolt had fundraised and crowd sourced over \$10,000 to take their dancers to



Sam with his parents Carol and Tom who feature heavily in the film

England and Cotton says those funds will be held until a new date for the Amici event is announced. In New Zealand, the film will be distributed to medical people like radiographers, midwives, nurses and doctors, to educators and trainee teachers to raise expectations, to schools and to the disability sector as a celebration of strength and being different.

“The experiences of our parents and other people within New Zealand to a Down Syndrome diagnosis continues to be negative,” says Cotton. “It focuses on all the problems that may occur. It is a culture of fear instead of expectation. It is also a culture that sees the disability as the most important factor in determining who a person is.” “We want this film to offer another side to the story. Sam’s life is one of purpose and love,” says Cotton.

Sam’s father Tom features heavily in the film, but unfortunately passed away recently before he could see the end product.

In the film he points out that most of us are stressed and can only see the problems ahead of us. “But not to one of these kids. Perhaps we should be more like them,” said Tom.



Sam Stevens performing in show about his own life



Amber Ranson on the set of Peninsula

THREE ACTORS LIGHT UP THE BIG SCREEN AND THE STAGE

By Coen Lammers



Poppy being shot at the Kapiti Coast

Actors with Down syndrome are becoming a hot commodity with three young female actors starring in two movies and a play in recent months.

Actors with Down syndrome are becoming a more regular feature on television and in movies, including *Coronation Street*, *Shortland Street*, and of course the current box office success *Peanut Butter Falcon*.

In New Zealand, Libby Hunsdale from Whanganui has been filming the movie *Poppy* at the Kapiti Coast, Lily Harper filled the lead role in the theatre production *Up Down Girl*, while Amber Ranson features in the short film *Peninsula* which was planned to be featured at film festivals overseas. Like the Hollywood blockbuster *Peanut Butter Falcon*, the New Zealand productions mostly centre around life with Down syndrome and the hurdles other people are putting up to stop people with Down syndrome to chase their own dreams.

Libby Hunsdale was picked for the title role of *Poppy* after extensive casting by writer and director Linda Niccol.

Niccol said that the 18-year-old was “a real find”. “She embodies the spirit of *Poppy*. She is a true performer.”

Finding the right actress for the role was challenging because the actor had to be able to drive a car.

Poppy is a New Zealand film about a young woman with Down syndrome who wants to become a motor mechanic, starting with the apprenticeship that was promised her by her late father. But Dave, her super-protective brother, who has reluctantly taken over the family garage is far from encouraging.

It is not until she teams up with a former school friend who needs his car fixed in time enter the local burn-out competition that her plans progress.

On the film set, Libby is supported by Sydney-based New Zealander Ari Boyland and another newcomer, Sebastian Hunter.

Producer Robin Laing said that it had been a steep learning curve for Libby who had previously acted in school productions. “But she has taken on the challenge with great courage and enthusiasm.”

In an interview with the *New Zealand Herald*, Libby said that she could relate to *Poppy* because she is ambitious and wants a career. “And I do too.”

“*Poppy* doesn’t care about what people think of her and the fact she has Down syndrome. I really relate to *Poppy*. We could be sisters.”

The film is currently being shot on the Kapiti Coast and is expected to be released in October/November.



Libby Hunsdale on set of Poppy with co-star Sebastian Hunter

The production received funding from the Film Commission's 125 Fund, in commemoration of women's suffrage in New Zealand, from TVNZ which will screen the film on prime-time television, as well as several other philanthropic supporters.

Another actress to soon feature at movie theatres in New Zealand is Amber Randon from Rakaia, south of Christchurch, who filled the lead role in the short film Peninsula.

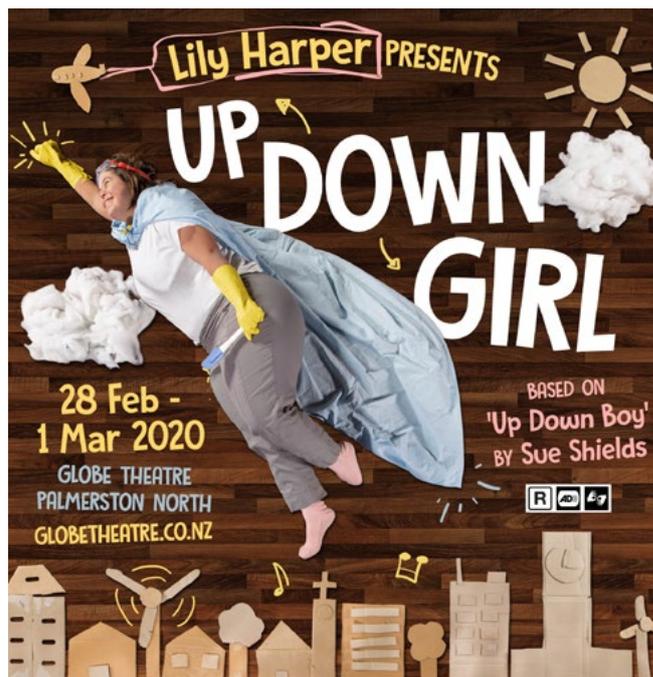
The short-film was written by Fiona McKenzie and filmed in Banks Peninsula last year, and was set to feature at overseas film festivals this year before it will be released in New Zealand in spring.

McKenzie had worked with Amber in acting classes and said she had written the story with Amber in mind.

"Amber's a strong performer and a strong character. I knew she was a strong enough person to enter a film set without blanching," McKenzie told Stuff.

"Also, when people see Amber in this film they'll think it's a film about Down syndrome, which it's not. I am so over these things having to be about disability just because people involved are disabled. Can't we move on?"

Amber's boisterous persona and sense of humour lit up the movie set and she said the film was "a



Lily Harper goes flying on the promotional shot for Up Down Girl

piece of cake".

"In one scene my character had to be dancing, so the crew put on Thunderstruck by AC/DC - one of my favourites. I busted the moves out and then off camera the whole crew was dancing with me." Another actor to steal the heart of her colleagues and the audience was Palmerston North's Lily Harper who received rave reviews for her lead role in the stage play Up Down Girl.

The play was originally written as Up Down Boy by UK-director Sue Shields, but adapted for New Zealand by Nathan Mudge who had worked with Lily on other projects.

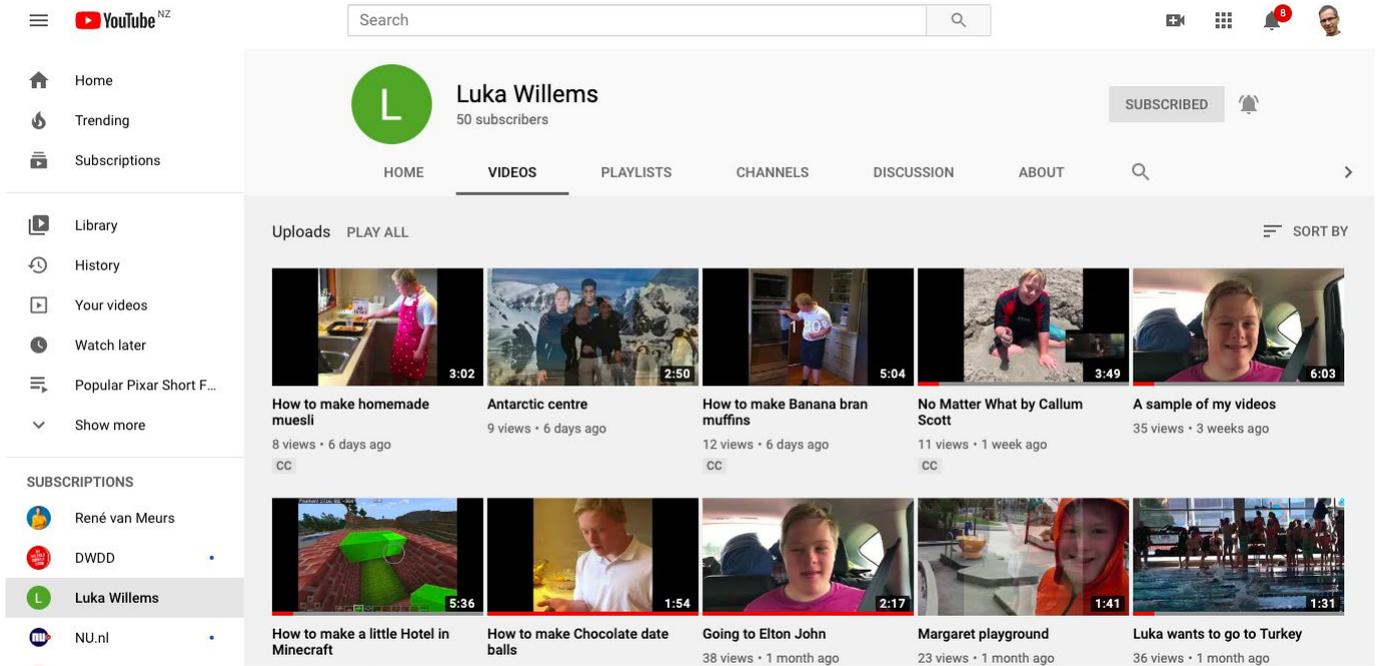
The play focuses on the main character Mattie and her interactions with her mother who is played by Trudy Pearson, as they are trying to prepare for Mattie to go to college.

The reviewer for Stuff said that Pearson carried most of the dialogue but that Lily "stole the spotlight".

Lily is a born performer and has already presented for Attitude TV and also features in the World Down Syndrome Day video message.

Up Down Girl however was her first stage play, but drawing on her own experiences as a person with Down syndrome, Lily nailed the performance and according to the reviewer there was not a dry eye in the house.

Down Write Brilliant



Luka shows his followers all the things he is up to in his life, like his cooking, his trips and his pets

MY YOUTUBE CHANNEL

By Luka Willems

I have a YouTube channel. I have clips about dancing, singing, cooking and things I do in the holidays. I love to record myself and let everyone know about interesting things. Maybe you will try to make date balls or soup. Just watch me to see how. Sometimes I video myself to make a clip and sometimes my family and friends video me. I put my thumb up to tell my family when to start. When the video is finished, I put it in iMovie. I edit it all by myself. I like to make new videos and I post them on a Sunday to spread them out. I have 43 subscribers and 668 views. I would like more subscribers because I want to be famous. Please search for Luka Willems to see my channel.





Leroy shows the way in the bush

EXPLORING THE BUSH WITH MY PARENTS

By Leroy Lewis

Last week our family took a long Waitangi weekend. We drove down to the Kaimai ranges, and tramped to a couple of DOC huts with a night on the coast in between.

The first track took us to the Te Whare Okioki hut. It was far from here to the hut.

This is a new hut on the site of the old

Ngamuwahine tent sites. It was a relief to see the junction as this told us we were close to the hut. We saw a dog and man and lady at the hut. The lady slept besides the campfire site. Mum and Daddy and I slept in the hut.

The second night we came out of the bush and stayed in a cabin by the sea. We went kayaking then we watched the 'Against the Wild - Survive the Serengeti' DVD. It rained during the night, but we were nice and dry.

The next night, we went back into the hills.

We stayed at a hut called Te Rereatukahia. There were 12 bunks and 15 people. Fortunately, we had a bed. It took us 4 hours to walk to the hut.

We met some children and played nerf ball. We played a card game called Go Fish.

It was cold out in the wind, but not inside the hut. I heard snoring during the night.

The next day we hopped in the car. We drove to a café in Waihi. I ate chips outside.

After that we went to a friend's place for afternoon tea. We went to home, then we unpacked. I had a shower.



Leroy enjoying the beautiful New Zealand bush



Leroy and his father Wynford enjoy the outdoors



The family regularly spends a night in DOC huts

Down Write Brilliant



Drumming to support NSW Fire Services



Emily drumming with her sister

I AM A TENOR DRUMMER

By Emily Gaede

My name is Emily I am in a pipe band. I play the tenor drum. I started in 2017.

In January I went to piping and drumming summer school with my sister and my friends.

This is my summer school band.

I played in grade 4 and my sister Anika played in grade 3.

Summer school was in Wellington, at Scots College. I made lots of new friends.

At summer school there was a mini band competition.

I played the drum and I did gymnastics. I did the splits!

We got third and everybody clapped.

Before summer school we did busking in town to earn money for summer school, but once we did busking for the New South Wales Fire Service. We raised \$ 280.00!

In February we had a competition.

We had to practise a lot, sometimes just with the drummers, sometimes with the whole band.

This is my band. In March we are going to Nationals. It will be fun!



Emily's fellow drum band



Drum summer school

Down Write Brilliant



Nic Wales and Tarryn Attwell

LEARNING NEW SKILLS AND MAKING NEW FRIENDS AT CREATIVE JOURNEYS

Creative Journeys, in Palmerston North, is a Social Arts & Performance Hub where people with Intellectual and Physical disabilities develop and explore their creative talents.

The hub staff, Rochelle, Sherryl, Kim and Rachel run day-to-day programmes, but people can drop in when they need.

The activities at the hub include just every artistic expression you can imagine, including drawing, painting, singing, dancing, tapestry, baking, sewing, woodwork and designing t-shirts.

The hub also gets a wide variety of visitors and guests, including a baby goat which got a lot of cuddles recently.

We asked the people using “CJ’s” if they could write what they liked about this very special place and this is what they had to say:

Jacqueline: I love all the staff at CJ’s. Because they help me, I like doing my art work and tapestry. I also enjoy cooking and knitting groups.

Sometimes I like to help out when I can.

Sally: I love coming to CJ’s to think outside the box. It’s fun here all the time. It’s fun to hang out with the gang.

Tui: I just love being here on Thursday morning because I love to sing, dance and art and craft I also love pretending to be Rochelle. I just love Rochelle, Sherryl, Kim and Rachel.

Mike: Reason I like coming to CJ’s is being with others. They encourage me to do more art. I also enjoy helping the others with their art projects. When I attend CJ’s it makes me feel really good inside.

Stephanie: I like coming to CJ’s and doing cooking and drawing. I like my scrapbook work and like working with Kate the artist.

Vanessa: I like CJ’s I enjoy cooking with Kim and doing art. I make amazing things at CJ’s. CJ’s makes me happy.

Conrad: I have been coming to CJ’s for 7 years. What I love the most about coming to CJ’s is meeting people and making really good friends I love hanging out with the friends I have made there.

Hamish: I love coming to CJ’s to help people and doing my art and woodwork. I also like going to the café on Fridays.

Timara: I love Rochelle and Sherryl. I love to go to the café on Fridays. I love meeting new people. I love cooking with Kim. I love being with my friends.

SPECIAL OLYMPICS CANTERBURY AWARDS

By Andrew Oswin

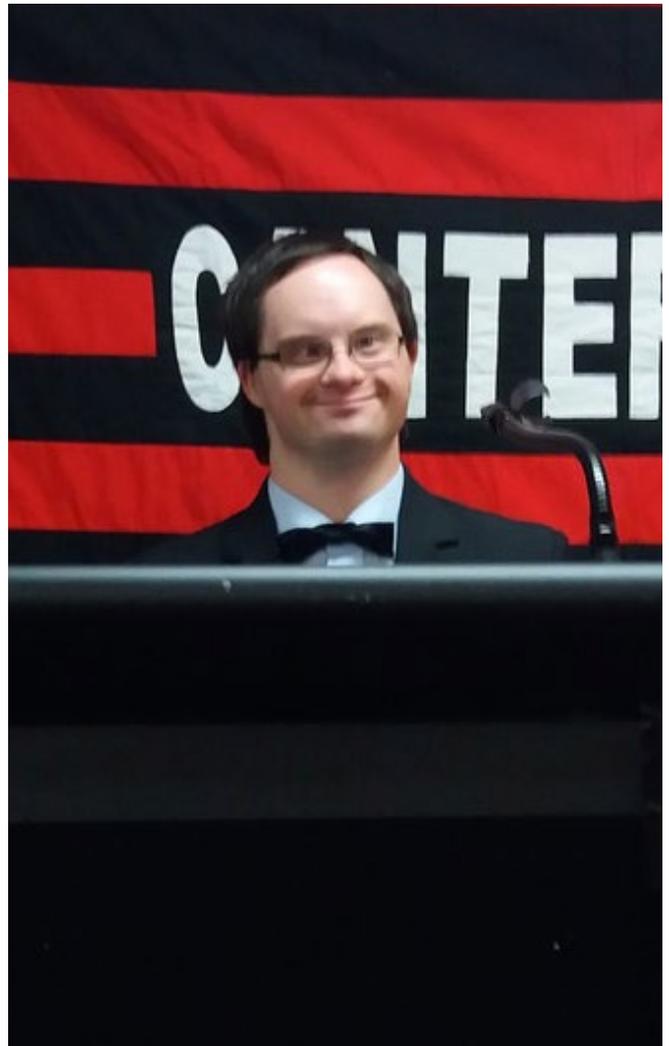
I was very happy and honoured to be the 'Master of Ceremonies' again for the Special Olympics Canterbury Awards, Dinner and Disco at the Hornby Working Men's Club in Christchurch.

It turned out to be an interactive, lively and motivational evening.

Everyone who attended enjoyed this event and had a great time dancing with their fellow athletes from every sport all throughout Canterbury.

The sport awards for this year recognised the achievements of athletes from 2019 and most importantly were filmed. The recording of the filming will be taken to the Special Olympics New Zealand's Head Office so that they can watch what we did.

I introduced all of my fellow athlete committee members to help to present the awards, and



Andrew Oswin at the awards

that also included me. After the official awards presentation we had dinner which the coaches and volunteers helped to serve everyone.

The final part to complete the evening was dancing with everyone having plenty of fun.

We danced to Mamma Mia, Dancing Queen, Moonlight from Michael Jackson, Grease Lightnin', Sweet Caroline and YMCA. The final song that got played to finish the disco was music from The Sound of Music.

I would like to thank the staff from the Hornby Working Men's Club for hiring their sports hall, Academy Engravers for engraving the trophies for Special Olympics Canterbury, Todd Quested for speaking on behalf as Chairperson for the Athletes' Committee, Helen Mitchell, Jeff Waters and my fellow committee members for hosting this wonderful event.

A very special thank you should go out to Jess Waters for the sound effects for the Disco.

Andrew Oswin is the Special Olympics Canterbury Vice-Chairperson

DOWN WRITE BRILLIANT - ME AND MY JOB

OUR NEW JOBS AT THE NEW ZEALAND DOMESTIC LOUNGE

By Mohit Chand

Veshaun Manikkam and I have been lucky to get a job at the NZ Domestic Airport working in the Lounge.

The lounge is managed by Compass who is our employer.

What Do We Do there?

Check in as we go inside so we can start our work, we have our own security pass. Our work clothes are as in the photo, we also have to use an apron. We get organised, put our belongs onto the tray our phones and bags too.

After we show our passes we are allowed to go to the lounge.



Mohit and Veshaun at their work at Air New Zealand

We start at 12.30 and finish at 6.00pm. We get picked up by our parents.

We are getting trained in doing our jobs properly and to a high standard level.

We like our new job and we come home happy because the job that we are doing in the domestic lounge just cleaning up the tables and chairs and taking all the dishes away and leaving the place nice and clean for the next guest.

We meet lots of people from different countries and enjoy talking with them.

The staff are friendly and makes us feel included. We would like to thank Crystel and Carlos for making this possible.

President's Pen

When I first started putting this president pen together my first thought was to hope you all attended and had a wonderful time celebrating World Down Syndrome Day events within your local community.

Unfortunately the COVID-19 Coronavirus has meant that these events have been cancelled countrywide, including the launch event for the NZDSA digital #We decide video.

Whilst the NZDSA is extremely disappointed at not having the opportunity to publicly celebrate our wonderful community, these cancellations are necessary as ours is a vulnerable community and we all are being exceptionally cautious to protect our wonderful loved ones.

Coronavirus is an unprecedented threat that each of us must take very seriously. I urge all of you to take all necessary precautions to keep yourselves and your families/whanau safe.

The Ministry of Health website is the best source of relevant information should you wish to learn more.

During these trying times when we need to practice social distancing I encourage you all to keep in touch with others in our community through ours and others Facebook pages, and through mechanisms such as Skype and Facetime and good old-fashioned phone calls.

Mostly be kind to each other, find ways to connect with your local community and help look after others that need help. And if you need help don't be afraid to reach out.

It's at times like these we see how fabulous human nature can be, in my local community and others there are already networks that have been set up to help those in need of a little kindness.

Despite the current health environment I hope you all took a moment to celebrate within your own family and I hope you've all had the opportunity to view the NZDSA #we decide video clip through links on social media and emails.

The #we decide theme is an international one that encourages everyone involved with our loved ones, from family to health professionals,



educators and employers, to remember that our loved ones are capable of making many decisions for themselves and deserve the right to decide what their good life looks like.

As their advocates we must remember to give them as many opportunities to be empowered to express their own desires and make their own decisions.

Sometimes this may not be by spoken word but by the behaviours they exhibit. I know that my son Brendon, who chooses to use minimal verbal communication makes his needs, desires and many of his decisions very clear through his behaviour!

It is important to learn to tune in to how our loved one uniquely makes their decisions obvious to us and practice letting go of making overriding decisions on their behalf, from personal experience that can be very difficult but I try.

Go well, Go safe,

Kim Porthouse

FRESH FACES INVIGORATE WELLINGTON DS ASSOCIATION

By James Webber
Wellington Down Syndrome Coordinator

The last few years have been a little tough for WDSA. But recently Deborah Jones twisted the arms of a few people and got some new blood on the WDSA committee.

Last year we spent a bit of time sorting out our contact list and systems (switching to Office 365). A huge thanks to Tim Waight from UDK Creative for his awesome design work and support for our new website <https://www.wdsa.co.nz/>.

We are particularly keen to hear from you if you know of any resources we are missing on <https://www.wdsa.co.nz/resources>.

Last year also spent some time getting our finances in good shape with some fundraising, thanks heaps to the committee, but particularly to Ruth Coard our fundraising ninja.

For this year we have some great family events planned <https://www.wdsa.co.nz/our-events/> including a couple of regional family days.

Our first event was in Masterton, as we had feedback about doing more in Wairarapa. We had a BBQ picnic at Queen Elisabeth park, rode the mini train and played mini golf. We had planned on doing some paddle boating, but the lake didn't have enough water in it due to the dry summer.

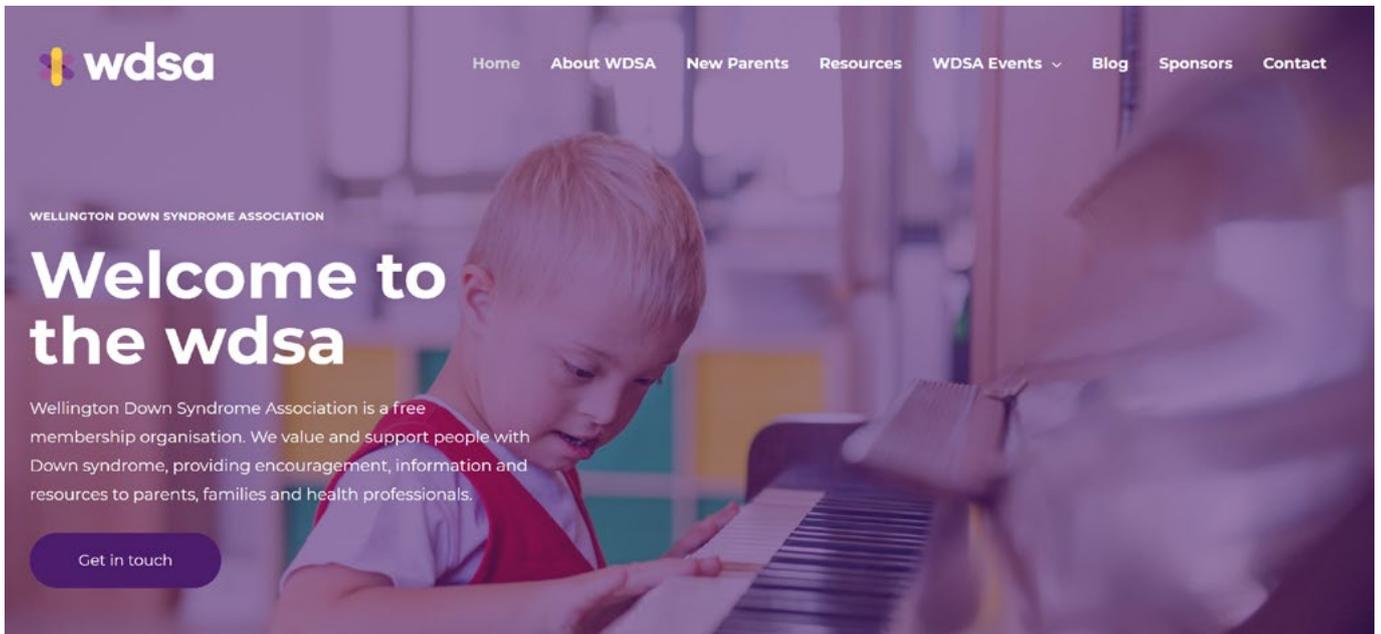
In June we are combining our AGM with some education seminars/workshops.

We are fortunate that Christian Wright is going to be speaking on behavior and Sue Elworth will be talking about her experiences of transitioning out of school.

Over the past year, we have been running a survey and got good feedback about what events people wanted and what they valued from WDSA. One key focus for us this year will be to reinvigorate our 'Age Group' catchups which had fallen away a little.

We used some of our funding to subsidise an online course 'Effective education for children with Down Syndrome in school' <https://www.wdsa.co.nz/2019/12/dse-ed-course-subsidy/> and this proved very popular with a range of parents, teachers and Ministry of Education staff signing up to start this year. We are working on other ideas for how to best help in the education space. We are also working on improving our connections with other organisations and linking into other resources.

If you are aware of useful resources the rest of the community could benefit from; we would love to list them here <https://www.wdsa.co.nz/resources/>



WDSA has produced a great folder for its members



The Wellington Down syndrome community is getting together more often



The children enjoying the BBQ picnic at Queen Elizabeth Park

A big challenge for us is getting people to sign up and keep their details up to date on our contact list.

We have lots of people connected via Facebook but who are not necessarily WDSA members (even though membership is free). NZDSA Wellington contacts and WDSA contacts don't always sync, so we did a big reconciliation and the committee have tried to contact old WDSA members, but please encourage your contacts to sign up <https://www.wdsa.co.nz/contact/> Related to this is a challenge of reaching new parents in the hospital.

Deborah and Ruth are doing a great job trying to address this. They are investigating posters in the hospitals and have created a new parent pack to

give to parents, but it's often very hit and miss if we find out about a new family in the greater Wellington region.

As with any group, administration can be time consuming. All our committee are volunteers but as we get larger and try to do more, we are going to need to investigate a paid part-time administrator.

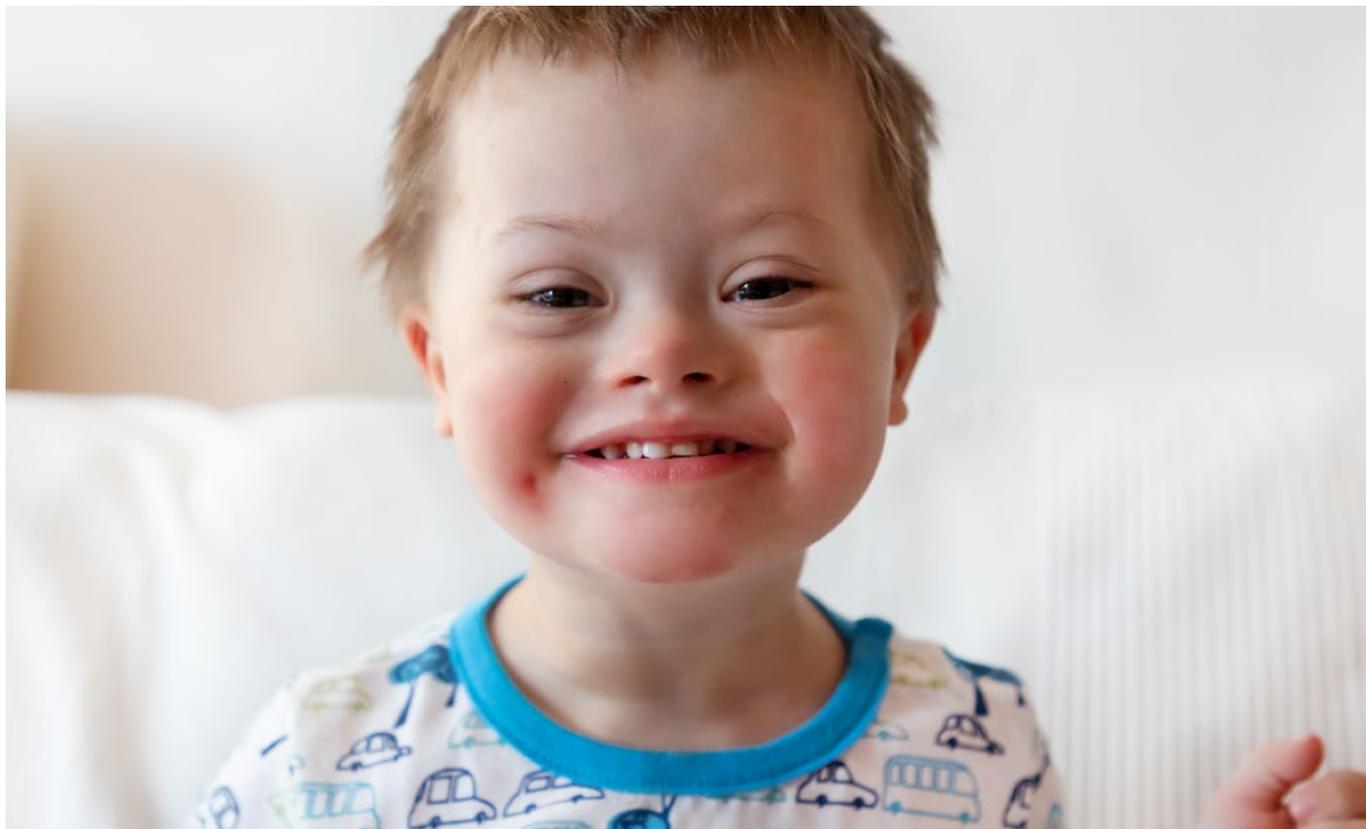
ORAL HEALTH MAIN CHALLENGE FOR PEOPLE WITH DOWN SYNDROME

By Linda te Kaat

Oral health is the greatest health need for people with Down syndrome. Oral disease shares common risk factors with cardiovascular disease, diabetes, cancer and chronic obstructive pulmonary disease.

What is dental disease, and can it be prevented?

- Decaying teeth: A cavity can result in tooth enamel dissolving over time. Early prevention can reverse tooth decay.
- Periodontal diseases: This affects the gums and bone around the teeth. Gingivitis is reversible and signs are red and swollen gums and bleeding on brushing. There will be no signs on an X-ray and no pain and may be present in more than one tooth. This develops more quickly in people with Down syndrome due to an altered immune reaction to plaque. Bacteria invade below the gums to cause inflammation which can lead to bone loss around the tooth root if not treated. X-rays are the only way to show if there is any bone loss. This also leads to bad breath and teeth can get loose or move and pain can occur on biting. There is often no pain in late stages of this disease and it always requires dental treatment.
- Trauma to tooth or jaw. Falls can cause dental trauma. Any tooth that has been chipped, moved or discoloured needs immediate treatments. Teeth that have been knocked out can be put back in again but never touch the root of the tooth and get the tooth to a dentist immediately. Dead teeth do not hurt but can be infected. Falls on the chin with problems opening the mouth may be a fracture to the jaw.
- TMJ (Temporomandibular joint & muscle disorders). This is caused by trauma to the jaw or TM joint or by grinding teeth from stress. That symptoms to look out for are pain or stiffness in the chewing muscles (often one sided), limited movement or locking of the jaw, painful clicking and popping or grating in the jaw on opening. This conditions tends to be more common in woman. The treatment is often simple and in most cases the discomfort will go away with little or no treatment. Eat small pieces of food, apply ice packs or heat packs. Avoid extreme jaw movements like wide yawning and chewing gum. Short term use of Nurofen may be useful.



Without X-rays, up to 40% of decay can be missed and therefore it is vital that these are carried out routinely.

Toothbrushing requires the same manually dexterity as handwriting and many people with Down syndrome find this difficult therefore regular dental care is required.

Often cysts may not be painful, and antibiotics can stop the pain and infection, but infection can still be in the bone and not picked up without an X-ray.

Chronic pain can lead to changes in behaviour and people with Down syndrome can have a high pain tolerance therefore once it reaches the level of pain it can sometimes be a major dental problem.

Always use toothpaste with fluoride in it and never rinse the mouth after brushing.

Savacol is good for plaque build-up and a mouthwash with fluoride is ideal. This can also be used on a toothbrush to brush around teeth if they person is unable to swish and spit.

The Oral-B electric toothbrush was also recommended as not only one of the cheapest but also the best to use but sometimes electric toothbrushes are not tolerated by our young ones, so use gradually to get used to it and start at a young age.

- You should seek professional care when there is:
- Any swelling of the mouth, face or neck.
- Any ulcer that does not heal
- Any persistent burning of the mouth
- Any severe pain in the teeth – even if it stops

For people that cannot explain their symptoms, watch out for a change in eating habits, oral behaviour or bad breath

Before going for treatment, discuss with the person with Down syndrome what is going to happen and use books to illustrate what they can expect.

Always keep the language positive and if possible try to have a first visit as an introduction without any serious treatment.

Linda te Kaat's article is based on the Down Syndrome New South Wales Health Conference she attended in Sydney.

PARENT CONNECTIONS PROVIDE INVALUABLE SUPPORT AND INSPIRATION

By Susan Foster Cohen
Director of the Christchurch Early Intervention Trust and Champion Centre

Raising a child with Down syndrome can be a better experience for parents if they are able to share their experiences with other families going through a similar journey.

The Champion Centre's model of early intervention has many essential elements that reflect best practice and one of them is the deliberate bringing together of parents with the hope that it will kick-start friendships and support networks between them.

By attending the Centre in small groups one morning a week during school terms, families not only receive individualised support for each of the children, but have frequent opportunities to meet and connect with other families/whānau whose children are at a similar age and stage.

Perhaps the most important moment in a Champion Centre morning from this perspective is the opportunity for conversation over a cuppa and a biscuit at morning tea.

This relaxed and necessary break from the focus



Susan Foster Cohen PhD

on each child's development is when parents can begin to learn each other's stories.

Group music is another moment deliberately designed into the model of service where parents and children can enjoy playing musically together. Sometimes the permission for parents to play results in more rowdy behaviour from the adults than from the children!

When it is time for children to move on to school, we hope that both the children and the parents will have formed bonds with other families that will serve them well into the future. We encourage parents to support each other in sharing information and advocating for their children as they go through life.

Chat 21 Editor Coen Lammers was one of the parents experiencing the benefits of that peer support when he was part the centre's programme with his daughter Bella and wife Suzi.

Bella and Coen recently presented to the Annual General Meeting of the Champion Centre to share



These Champion Centre parents still get together for Christmas and provide support to each other, even 13 years after their children have left the centre

their experiences and talk about the continuing value of the peer networks in their lives.

Bella spoke about her school, her work, her sports, her dancing and her social life, where in many cases she still enjoys the same friendships she developed when she attended the Champion Centre more than 13 years ago.

The 18-year-old still hangs out with the UPP Club Christchurch, dances at Jolt and swims against the same young men and women, she learned to crawl and walk with as a toddler.

At that same AGM, her dad explained that the connections for the parents are also still just as strong and just as important.

“We are lucky that the “Class of 2001” brought together a group of parents that instantly clicked, and we still see each other regularly,” said Coen. He said the families get together regularly for birthday parties and other key events, and have created a Christmas meal tradition where the children are not invited.

“The interesting thing is that at the start we often talked about our children, about schools, funding or health issues, but as the years progressed, we have just become really good friends, well beyond the Down syndrome connection.”

“That connection brought us together, but is not why we get together. Saying that, having this group of parents still provides support when we need it, an opportunity to share information or spark some inspiration if we see one of the children doing something amazing,” says Coen.

NEW PROGRAMME TO GET YOUNGER CHILDREN INVOLVED IN SPORT

Staying active and being healthy is important for everyone. But – even from a very young age – children with an intellectual disability often feel left out from sports.

Special Olympics New Zealand wants that to change and are working on ensuring everyone is given the chance to take part in sport.

The Young Athletes Programme, run by Special Olympics, promotes motor, social, and cognitive development in children through physical activity and play.

The programme is aimed at children 2-7 years old. It's an opportunity for children with and without intellectual disabilities to play together and understand each other. It encourages more inclusive play in schools, communities and homes. For many children, it will be their first introduction to sport, so the activities and games are specially planned to meet their skill and ability levels.

Some of the fun activities include bubble play, catching and kicking balls, balancing, bowling, and working with tennis rackets and hockey sticks.

The equipment used is big, bright and bold, with a giant colourful parachute being a favourite for many of the children!

Research shows that children with an intellectual disability who take part in the programme more than double the speed that their motor skills improve, compared to those who don't.

More than this, the confidence the programme builds in children is priceless. One parent noted that before joining the programme, her daughter didn't like taking part in sports at her school. After only a week in the Young Athletes Programme she announced, 'I love sport!'

It's amazing just how quickly the children learn in the programme. Key to this success are the high coach to participant numbers. This makes sure every child can develop their skills in a safe, welcoming environment.

The assistant coaches include Special Olympics New Zealand Athletes, who themselves have intellectual disabilities. This shows the parents and children that they too can aspire to become athletes. And it has the added benefit of helping the athletes develop their coaching skills.

After a successful pilot in Wellington last year, Special Olympics New Zealand are hoping to roll out the programme across the country and have plans to run two programmes in South Auckland in 2020.

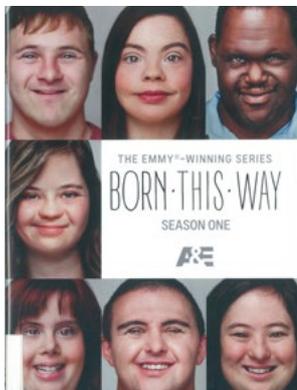


Wellington youngsters enjoying the pilot programme developed by Special Olympics to attract younger children with disabilities to sport.



IHC Library

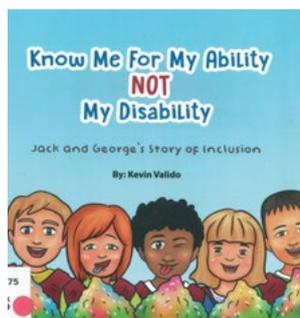
To celebrate the World Down Syndrome Day theme of “We decide” we look at resources in the IHC library that tell positive stories of people with disabilities who have made decisions, sometimes with support, to live the life they choose.



Born this way. Season one DVD

This DVD offers an intimate look into the lives of seven young men and women born with Down syndrome, along with their families and friends.

Cameras follow the young men and women as they pursue their passions and lifelong dreams, explore friendships, romantic relationships and work, all while defying society's expectations.



Know me for my ability NOT my disability: Jack and George's story of inclusion by Kevin Valido

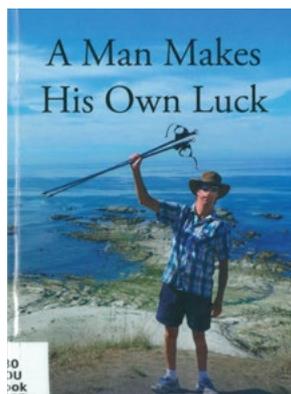
One summer, best friends, Jack and George, decided to

go to summer camp together. Little did they know that their parents would send them to a camp built on the idea of having an inclusive environment for all people.

Their plans of spending time together take a turn when they are placed in separate groups. On their adventure, however, they encounter new friends with a wide range of different abilities. Through the eyes of the children in the camp with special needs such as spina bifida, Down syndrome, and autism, Jack and George get to see how our differences are not what define us.

Rather, the boys learn a valuable lesson. They realise that it's important to know each other's abilities and not focus on our disabilities.

Jack and George learn through their new friends that our differences truly are what make each and every one of us beautifully unique.



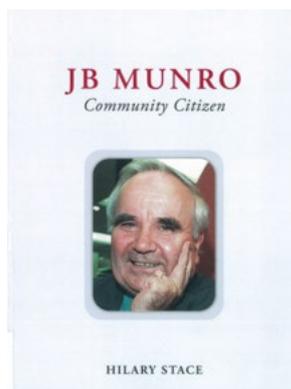
A man makes his own luck by Daniel Younghusband.

This book is the next step in a lifelong journey towards achievement and big goals.

In spite of being legally blind, a Type 1 diabetic, and being born with

a rare form of dwarfism, Daniel has led a full life; from growing up in Africa with plenty of adventures in the bush, to immigrating to New Zealand at the age of 18 with his family.

He doesn't believe 'disabilities' should hinder anyone from achieving their goals or ambitions, and he hopes this collection of his own life lessons and overcoming obstacles will inspire others to push themselves and make their own luck in life.



J B Munro: community citizen by Hilary Stace

JB Munro led the IHC for two decades in an era of a growing disability rights movement, the closure of institutions and calls for self-advocacy and citizenship by people

with intellectual of learning disability.

As a child, the state ward and polio survivor was adopted by the Munro family of Invercargill. He trained and worked as a youth worker.

His long career leading the IHC started in 1977 and after stepping down from that role 21 years later he continued his work with Inclusion International. His busy retirement continued a focus on community.

Our team member Michael has just read it and really enjoyed it. “A good read and great photos.”

Please contact your library team (Phil, Ros, Ann and Michael) on 0800 442 442, email us at librarian@ihc.org.nz or visit the online catalogue at <https://ihc.mykoha.co.nz/>

You can watch our library video at <https://www.youtube.com/watch?v=AunmBYTIZTM>

NZDSA notices

Youth Development Camp

Whilst things might still be uncertain, we are hopeful that the 2020 Youth Development Camp will still be hosted from Friday the 27th November until Sunday the 29th November 2020 at Vaughan Park Retreat Centre, Long Bay, Auckland.

This year the NZDSA National Committee has indicated that the 2020 camp will be focussed on youth who have additional support needs.

The NZDSA is calling for expressions of interest from NZDSA members over the age of 18 with Down syndrome who would like to attend this camp. Please note that this camp is for members who are not able to attend a camp independently and require a parent or guardian to attend the camp to assist with their additional support needs. Please note that we have limited places on offer, so please email Linda on nzdsai@xtra.co.nz by the 27th April 2020 to register your interest.

Rose Award

You will note that no one was nominated for a Rose Award in this edition of CHAT 21. So, I would like to encourage you to nominate a deserving individual or organisation for the next edition of CHAT 21.

The Rose Award provides the opportunity to thank individuals or organisations who either support individuals with Down syndrome or the Down syndrome community. Please email Linda at nzdsai@xtra.co.nz your nominations for an individual, family, or organisation explaining what they have done to “promote the participation of people with Down syndrome in their community”. We will acknowledge the person in CHAT 21 and will post them a letter outlining why they were selected and include a box of Rose’s chocolates.

Top 10 Maths Applications

The NZDSA would like to know your favourite apps for maths. Please email your list to Jess at hello@nzdsa.org.nz

The NZDSA is calling for nominations for the NZDSA 2020 National Achievement Awards.

These awards recognise the accomplishments of people with Down syndrome during 2019.

If you would like to know how to nominate a person please email Linda te Kaat at nzdsai@xtra.co.nz.

Thanks

Thanks to the following funders and sponsors who have made donations to the NZDSA this financial year:

- Joyce Fisher Charitable Trust
- Lottery Minister’s Discretionary Fund
- NZ Lottery Grants Board
- Holdsworth Charitable Trust
- Thomas George Macarthy Trust
- Pub Charity
- Southern Stars
- Enable NZ - Mana Whaikaha
- COGS Christchurch
- COGS Hamilton
- COGS Manukau
- COGS Manawatū/Horowhēnua
- COGS Otago
- COGS Whangārei
- COGS North Shore
- COGS Wellington
- COGS Southland
- Page Charitable Trust



The NZDSA has a Facebook page that serves as a community forum and notice board for relevant issues, events and stories.
Please check it out at facebook.com/NZDSA

Contact Directory

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	<p>Angelique van der Velden Zone 5 Representative Ashburton & all areas above 0800 693 724 press 2 zone5@nzdsa.org.nz</p>	<p>Averill Glew Zone 6 Representative All areas below Ashburton 0800 693 724 press 3 zone6@nzdsa.org.nz</p>	<p>Shelley Waters Treasurer treasurer@nzdsa.org.nz</p>
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	<p>Daniel te Kaat Graphic Designer 021 22 333 93 daniel@slaughterhaus.co.nz</p>	<p>Jess Waters Social Media and Information Officer 021 032 8539 hello@nzdsa.org.nz</p>	<p>New Zealand Down Syndrome Association PO Box 4142, Shortland Street Auckland, 1140 0800 693 724</p>
Regional Liaison Officers	<p>Auckland Community Liaison Officer 0800 693 724 press 3 clo@adsa.org.nz</p>	<p>Donna Higgs-Herrick Canterbury Community Liaison Officer 0800 693 724 press 3 cdsainc@gmail.com</p>	<p>Sandra Slattery Taranaki Community Liaison Officer 0800 693 724 press 3 taranakidownsyndrome@gmail.com</p>

NZDSA Membership

Membership charges are as follows: \$30 one year Financial membership fee, \$50 one year Affiliate membership fee, \$15 one year Self-advocacy membership fee. To obtain full details and a membership form please either email - nzdsai@xtra.co.nz or telephone 0800 693 724 ext 2.

Database Updates

The NZDSA would like to update their database. If your details need updating please contact us either by email - nzdsai@xtra.co.nz or telephone 0800 693 724 ext 2.

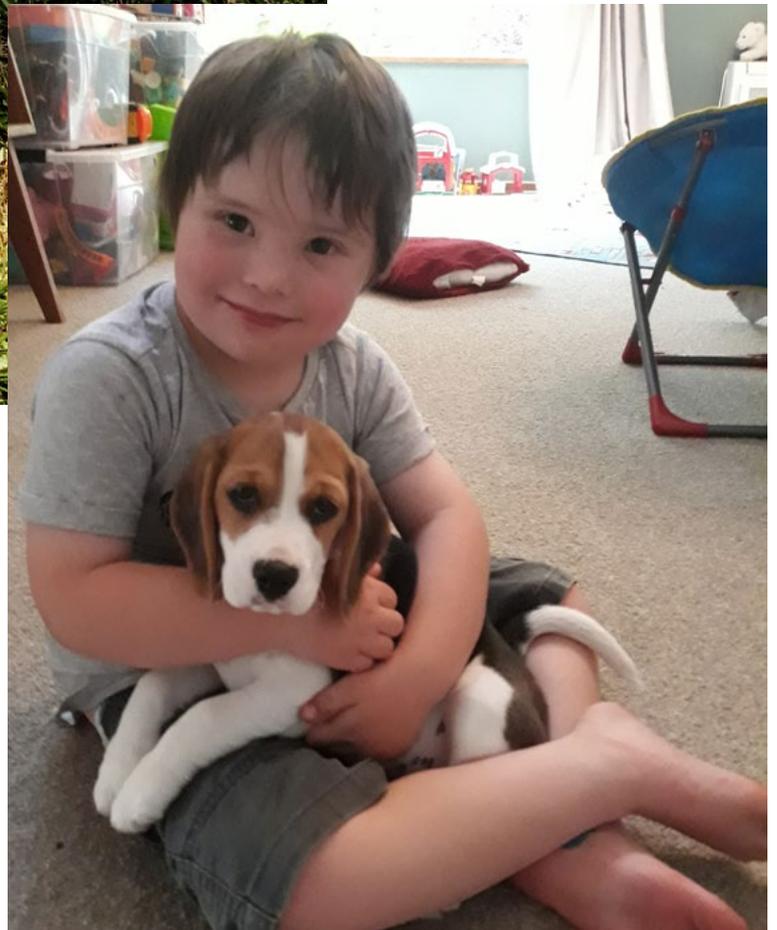
Donations

The NZDSA receives no Government funding and relies solely on donations and grant applications to keep us running. If you are able to make a donation please either send a cheque to us at P O Box 4142, Shortland St, Auckland, 1140 or direct credit to ASB 123073 0090784 00 using your surname as reference. If you require a receipt please email us to let us know you have made a donation via internet banking by telephoning 0800 693 724 extension 2 or emailing nzdsai@xtra.co.nz. If sending us a cheque please include your address so a receipt can be posted to you.

Me and my pet



**MASON
HARKNESS
WITH ONE OF
HIS FURRY
TRIBE**



**KEATON
BONSOR, 5,
WITH PUPPY
MISTY**

Our people



Mason Harkness with brother Devon



Freddie Finch eating a Kiwi icecream after his move from UK



Jackson Backhurst, aged 9 months



Lulu celebrating her first birthday on 23rd December 2019