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PRESIDENT SPEAK



Hello everyone:

This year has been quite eventful for APDSF so far. With events like the World Down Syndrome Day celebrated in March across various countries and the Federation's representation at the UN being widely appreciated, it truly is a good start.

At the UN, Dr. Surekha Ramachandran representing the APDSF spoke about a taboo topic – “Genetic Culling” which received tremendous praise. This was the first time in the history of the General Assembly that someone spoke on this controversial topic. Members from APDSF – Dr. Lalita Joshi of Nepal and Dr. Bhavani Sriram from Singapore also spoke at the UN.

Our medical committee led by Dr. Bhavani Sriram is also trying to build a team of medical experts across the APDSF region. She has been asking for representatives from the various countries to volunteer for helping persons with Down syndrome and their families to understand the health aspects better.

We are also planning the next AGM of the APDSF countries at Colombo tentatively from the 7th to the 9th of December 2018.

We are looking at reaching out to many more countries that are yet to understand Down syndrome and assist them by spreading awareness and providing information that we have at our disposal. This is our contribution in making the region a Down syndrome friendly place.

Wishing everyone the very best.

Regards,
N. Ramachandran
President - APDSF



INDIA

The 2nd India International Down Syndrome Conference 2018

The Down Syndrome Federation of India (DSFI) organized the 2nd edition of the India International Down Syndrome Conference (IIDSC) at Pune, India from the 31st of May till the 2nd of June 2018.

IIDSC 2018 and Hamsafar was a unique program that provided an energizing and informative list of speakers who engaged the attendees and facilitated networking opportunities for parents. **While IIDSC is the conference that DSFI has been organizing, Hamsafar is a program started by DSFI for parents of children with Down syndrome. This is a platform for parents to interact with each other and obtain best practices for a better future for their children.** IIDSC 2018 was formally inaugurated by the Municipal Commissioner of Pune, Mr. Saurabh Jain, IAS.

Dynamic researchers, physicians and therapists – **both National and International** - presented cutting edge translational medical research and potential interventions to improve the health, cognition, behavior and development of individuals with Down syndrome. **Indian speakers included famous doctors like**

- **Dr. Koumudi Godbole – a renowned geneticist**
- **Dr. Vaman Khadilkar – leading endocrinologist**
- **Dr. Usha Pratap – a well-known paediatric cardiologist in the region**
- **Dr. Mohan Kameswaran –ENT specialist**
- **Dr. R. Sankar – a popular paediatric orthopedician**
- **Dr. Nikhil Rishikeshi – renowned eye specialist from Pune.**
- **Dr. Priya Chandrasekhar – Pediatrician specialising in children with Down syndrome**
- **Dr. Shaji Thomas John – consultant paediatrician who also won the best paediatrician award from his state.**

This unique conference drew an audience from across the country, including practitioners, representatives of related organizations, caregivers and advocates who were motivated by the common goal of enriching the lives of people who have Trisomy 21.

Attended by almost 400 people, this Conference was a double delight for families with mornings engaged in seminars and lectures by eminent experts and evenings providing fun elements like cricket matches and a Toga night where all delegates came in traditional Greek Togas to brighten the mood of the event.

The closing ceremony on the last day ended with the presentation of the DSFI Excellence Awards. The DSFI Excellence Awards were presented in the areas of self advocacy, research for Down syndrome and efforts put towards the cause of persons with Down syndrome and helping them lead meaningful lives.

It was a time for bonding and sharing for all the delegates who had a lot of learning mixed with fun.



Traditional outfit -inaugural day of IIDSC 2018.



A team all set to play Cricket



Toga night.

AUSTRALIA



Down Syndrome Australia's Down Syndrome Advisory Network

Down Syndrome Australia recognises the importance of keeping the voice of people with Down syndrome at the heart of the work we do. To address this need—thanks to the support of the Sherry-Hogan Foundation—we have established the Down Syndrome Advisory Network which consists of people with Down syndrome from across the country who bring their lived experience and opinions to the table. Members are supported in their roles to attend meetings and share their experiences.

In October of 2017, DSA celebrated the first meeting of DSAN where members met each other and the DSA board. Since then, DSAN attended the WDSD event at Parliament House in Canberra as well as contributing to various submissions and projects. Members of DSAN were recently interviewed for the April issue of *Voice*, the journal of DSA and spoke about their reasons for joining the network:

Andrew Domahidy

Andrew is a busy man with a wonderful sense of humour and an interest in meeting new people.

'I do swimming three times a week and I am starting Tae Kwon Do...self-defence. I like to socialise with my family and friends by going to the movies and things like that. I go up to the bowling club for a few drinks, drinking till all hours of the morning!

'I live in my own flat and I have a double bed. I do my washing on the weekend and I like playing play station too. I like being on the computer too and I use social media. I'm on Instagram, Facebook, Twitter...all the majors. I use it to meet people and try to meet girlfriends and have a relationship. I'm looking for a girlfriend at the moment because I would like to have a family one day but I haven't really got around to thinking about it much though!'

Andrew says that being a part of DSAN is a lifetime goal for him to be a part of it. He has done lots of public speaking before and is a member of a lot of clubs. He likes being on

committees and enjoys doing paperwork and computer work. He wants people to learn more about Down syndrome by hearing the things he has to say about himself.

Andrew believes that people can learn more about Down syndrome through journals like *Voice* and social media by getting more people here and overseas to read about Down syndrome. 'We could send it overseas and get half a million people to read it. Then people could learn more by me talking about my life', he says.

Claire Mitchell

I live at home with my family. I have my own flat under the family home in the south of Queensland. One of my favourite things is public speaking. I love it. I love being able to help other people especially those who are under 30. I work in the Children's Hospital at Lady Cilento. I am an office administrator.

Why did you want to be a part of DSAN?

Mainly because I am interested in employment and people having jobs and I think that everyone needs to have a voice and to be heard. It was wonderful being in Melbourne and meeting everyone who was the chair of their states. I like meeting new people. I like people more than I like animals.

How will DSAN help the organisation?

I would like to think it can help every single aspect including aged care. It's really important to think of everyone. I think that when you are trying to make a decision you really don't want those decisions made for you. You want to be making them yourself.

I want a happy and healthy life that everyone is able to achieve. I want to be like everyone else. Everyone needs to be working and you need a job that suits you.

What do you want people to know about Down syndrome?

It's not something to be frightened of. People shouldn't be frightened to come and talk to us. It's important for people with Down syndrome to be heard in their own words. For people who struggle with communication, there are other things out there to use. Disability Standards are done by pictures or if you know sign, you can use that.

Kylie Scott

I am involved in Uni2Beyond. It's a program for people who have intellectual disability at Sydney University. I live independently in a private rented apartment. I am on the Sydney Local Health District NDIS Governance Committee and the Centre for Disability Studies Joint Research Committee.

I also have my business (kyliedownsbarriers.com.au) which is public speaking and arts. I talk about examples in my life to help people understand and learn from people with Down syndrome and intellectual disability.

Why did you want to be part of DSAN?

It means a lot to me to be part of DSAN. It's exciting. People with Down syndrome need to find a way and be free to have a voice. I will advocate in the meetings and use the skills I have learnt. When I was little, mum and dad showed me how to do things. I'm really close to my mum and dad.

What was it like meeting the other members of the network?

It was a challenge for me. We all have different voices, different names and different faces. It was great.

What do you want people to know about people with Down syndrome?

We have the same skills and experience. I want families more involved. Communicate with people with Down syndrome more, get them in the centre more...person-centred. I want people to ask me what I want. I want World Peace.

What can society do to make things better for people with Down syndrome?

Be welcoming in the community if they are out in the community activities. Their NDIS plan helps them get into the community. The planner comes to you and you can ask for things, they help you out. If you don't ask you don't get.

Take one step at a time.

Michael Sullivan

Michael Sullivan is an experienced and seasoned advocate for people with an intellectual disability. He was Chair of NSW Council for Intellectual Disability from 2015–2017. He has previously been on the National Disability Advisory Council in Canberra and currently is on the National Disability Insurance Agency Intellectual Disability Reference Group. Michael is also the Australian representative for Down Syndrome International (self-advocacy group) and the Healthy Ageing Ambassador for the UNSW Department of Developmental Disability Neuropsychiatry. Therefore, Down Syndrome Australia is thrilled that Michael can bring his experience to the network.

When asked about his role in DSAN, Michael says:

'It's important to be part of the DSAN, to get to meet all the other representatives of the states, and to get to know them.'

It's always important to meet the people you are going to work with and for in person. Meeting the team and the network for the first time is really great.

Having Down syndrome, we are no different from anybody else: all we want is to be treated with dignity and respect.

Being the international rep, on Down Syndrome Australia, I will work on anything special that needs to be addressed.'

Nick McMahon

Nick is 27 years old and lives in Adelaide. He is an active member of Down Syndrome SA and is a part of many of their programs including Life Ed classes, Club Slick and Club Strike activities. He loves rock'n'roll dancing and has performed at World Down Syndrome conferences with his dance group.

Why is it important to be a part of DSAN?

So I can be myself independently sometimes, and to help other people with Down syndrome.

What was it like meeting the network and the team?

It was good with everything—to meet the team and good to stay in Melbourne and go to the meeting.

What do you want people to know about Down syndrome?

We have fun and hangout together with friendships and dancing

How will you help DSA with their work?

I will do apparently any kind of work to help, and how to help them learn dance, but not be overprotective with friends.

Matthew O'Neil

Matthew is 22 years old and from Melbourne. He has a very busy life working at number of jobs—both paid and volunteer—in retail, hospitality and as an assistant basketball coach.

'I'm alive and healthy. I get on well with my family. I have a voice and an opinion and enough money. People with disabilities are important to other people.

I have a good attitude and stay calm and strong through tough times.

I like to share the love with family and friends and like to feel loved.
I like cracking jokes and being a bit silly.
I like to stay positive.
I would rate my life 10/10.'

He said being part of DSAN was to be a role model and to inspire other people with Down syndrome.

When meeting the team and network he was nervous but hoped that he made a good impression. He is still learning about the process and enjoyed meeting a politician from Canada. He was keen to tell others about the difficulties he experienced in a mainstream school and hoped that it did not happen to others.

He says, 'Other people should know that people with Down syndrome have some similarities and some differences. They are more vulnerable and may need additional help. People need to know that people with Down syndrome need to have jobs, somewhere to live, money and be able to spend time with family and friends.'

Matthew is red hot to go as part of the network. He will go to all of the meetings, go to fundraisers and spoke as a representative of DSAN to a workshop run by VALID recently.

Ebony Beveridge

Ebony (21) is currently focusing on moving towards independent living, enjoying a very active lifestyle and is a keen voice for people with Down syndrome. Ebony has presented to a number of audiences including service clubs, TAFE Individual Support students and Down Syndrome Tasmania's professional workshops for teachers and teacher's assistants. Ebony is doing work placements with Family Day Care and the School of Special Education and is a member of the BrightStars Dance Troupe, does hip-hop dance classes and regularly attends the gym. Ebony is experiencing great support and benefits from her NDIS plan and team.

These interviews first appeared in *Voice*, the journal for Down Syndrome Australia, April 2018.

To subscribe to *Voice* please go to this link
<https://www.downsyndrome.org.au/journal.html>



MONGOLIA

SELF-ADVOCATES ON EDUCATIONAL TRIPS TO REMOTE AREAS OF MONGOLIA

Down Syndrome Association Mongolia keeps raising awareness on Down Syndrome and calling for inclusion organizing educational seminars in provinces, delivering most important information for nomadic families with disabled children, and children with Down Syndrome, in particular.

Sometimes we organize the seminars jointly with Autism Association Mongolia and Special Olympics Mongolia providing larger scaled information on intellectual disability in general.

It is fantastic to see how nomadic, rural families, teachers, medical doctors, social workers and administrative staff get inspired after our trainings and case consultations, and we are greatly thankful to Shangri-La Hotel Ulaanbaatar for generous sponsorship and making these positive changes happen in local communities. .

Number of rural families from Middle Gobi, South Gobi, Selenge, Darkhan-Uul, Orkhon and Dornod Provinces have become members of our Association, discovering a source of very important information on Down Syndrome and inclusion. We continue receiving in our UB Office more and more seekers from each of the provinces where the seminars took place.

By now, DSAM has reached seven remote areas of our country /Middle Gobi, Selenge, 2 districts in South Gobi, Darkhan-Uul, Orkhon, Dornod provinces/ and about 550 rural parents and specialists have been involved in our educational seminars by April 2018.

Besides basic understanding of the subject /Down Syndrome/, and skills to support these types of children, our audiences sensed an importance of personal responsibility and personal participation in changing social attitude towards those who live with intellectual disability.

Truly, the most inspiring presenters of the seminars have been self-advocates with Down Syndrome and their parents! /Pls refer to attached photos/

Together with the training team, they use trains, buses, shared vehicles (sometimes covering hundreds of miles for 10-11 hrs daily !) to reach the destination.

How nice to be a part of dynamic training teams and enjoy a shower and delicious meal after heavily busy days!

DSAM planned five seminars in May, before school vacations start – two Northern provinces, two in Gobi Desert and one at Western edge of the country. Educational seminars will keep going until the last from all 21 provinces of Mongolia is done.



MYANMAR



Myanmar Down Syndrome Association

1. Myanmar Down Syndrome Association was conceived to form by the meeting of Daw Myo Pa Pa, a parent of child with down syndrome and Daw Nwe Ni Aye, Chairperson of Future Stars Special Needs School by the introduction of Ms. Kakio in 2014 while they were attending the APDSF's 3rd Annual Meeting with the invitation of Mr. Kizuhira of Japan Down Syndrome Association.
2. In February 2015, fifteen persons including members of Special Needs Schools, Down Syndrome family members from sports organizations met at Myanmar Autism Association's office and formed working committee. Since then, World Down Syndrome Day and World Down Syndrome Awareness months were celebrated annually and monthly respectively. It has even already celebrated World Down Syndrome Day for four times.
3. The Down Syndrome Association has been standing as a government recognized organization which is leading the Down Syndrome and its members in Myanmar.
4. Educating and examining the dental and oral cavity health and hearing assessment for Down Syndrome persons were already conducted successfully organized by the Association at State run hospitals with special programs. In 2017, Down Syndrome from Mandalay, capital of Upper Myanmar and other Down Syndrome received those kind of health screening programs.
5. The association has been providing healthcare programs for Down Syndrome. Moreover, it also provide programs for prevention which are necessary of developing countries. Guide line medical passports will be distributed to DS families in Myanmar by sharing of Dr. Shaji Thomas at 4th Annual of Asia Pacific Down Syndrome Federation.
6. Moreover, MDSA formed its health, social and educational sub committees in November, 2017 and activities on the sectors will also be conducted with the help of the sub committees.
7. EC members and members of sub committees have been working at Advocacy Concepts and Strategy Development Training, project cycle management and financial management and SWRR's Early Childhood Intervention (ECI). It has also been attempting

to implement an Intellectual Disabilities family network with the cooperation of intelligence (intellectual) organizations and the members also attend trainings of refresher (upgrading) courses.

8. Total of fifteen persons including Chairperson Daw Myo Pa Pa, Vice Chairperson Daw Than Than Maw and Secretary Daw Saw Ekari Htut, attend a five week training with the invitation of Flinders University in Adelaide, Australia and they are preparing to work for people with Down Syndrome in Myanmar.

9. Moreover, Chairperson Daw Myo Pa Pa proudly received APDSF Excellence Award of Outstanding Effort for the course of Down Syndrome in Asia Pacific Region at 1st India Down Syndrome Conference.

10. The Myanmar Down Syndrome Association will work for the benefits of APDSF families and Persons with Down Syndrome as much as they can by making effective policies.

A Painter, a dancer and a true hero - Aung Lin Htutwas

Aung Lin Htutwas was born with Down syndrome in 1998. He started schooling in Eden Center for Disabled Children (ECDC) since February 2007. He could speak some words but not clearly. His concentration was weak to initially. He was not able to write but could handle the color pencil to do scratching and haphazard coloring. Most personal cleanliness and daily routine activities were mainly with assistance from his mother DawThan Than Maw. His development process was still in the stage of learning for about 3 years in ECDC. With the support of his mother and teachers from the school, starting from the age of 12, he commenced to take care of the daily activities on his own. He progressively improves and grows by learning, participation, caring, assisting the classmates and teachers.

Awards and Achievements

1. Coloring Contest achievements at school
 - 2006-2007: Second prize
 - 2014-2015: Second prize
 - 2015-2016: Third prize
 - 2016-2017: Second prize
2. Dance Performance achievements at school
 - 2015-2016: First prize for Group dance
 - 2016-2017: Second prize for Group dance
3. 2017 Special Olympic (National Level) Games Competition awards
 - Gold medal for 100 meter running competition in 2010 and 2015
 - Silver medal for 100 meter running competition in 2016
4. International Disable Day dance Competition: Achieve second prize

Special skills: playing guitar and dancing

Membership: Member and a volunteer of Myanmar Down Syndrome Association
A volunteer of Myanmar Autism Association

Significance of Contribution

Contribution at home

Aung Lin Htut could wash his clothes, prepare meals and eat on his own without any support from his mother at home. At school he could color pictures and even win prizes for his achievements. Moreover, he was able to write his name, family members' name, home address, telephone number, other words and phrases. He readily learnt to use the computer and even assisted his family members with the computer. He corrected the mistakes by his mother by referring books.

Aung Lin Htut shares duties and responsibilities at home. He helps carrying errands for his mother like shopping. He also takes care of the house when the family members are away to the office or to schools in weekends. He is able to use mobile phone and can respond with appropriate responses when the calls come in from the friends of his parents. He can play a guitar and sing songs for his leisure. He schedules the daily activities, tables the time for home work, household chores and leisure on his own.

He can claim his rights from the parents on what he needs and what he wants. (Examples:demands new Samsung mobile phone for the replacement to the older one. He recognizes the phone card expiry and asks for new substitution. He asks his mother to buy new clothes for his birthday as a gift and demands to celebrate a party for his birthday at school).

Contribution at School, Eden Center for Disabled Children

Aung Lin Htut is a mentor in his class. Every day at school, he is responsible for collecting the attendance of each class and the attendance list is pasted on the wall of each class. He does the task for 5 classes every day. He delivers snacks to each class room every day. He assists teachers feeding meals to the children with Cerebral Palsy.

At ECDC, he assists the class teachers to observe the younger children and the classmates. He consoles his quarrelsome classmates with compassion and care. With his social interaction skills he can guide the visitors on a tour around the ECDC.

He can perform dances very well and is competent enough to participate in contests. He has won prizes in dance competitions. He was selected to take part in the dance performance program at the First National Education for Children with Disabilities event in Myanmar.

In addition, he is competent enough to participate in the Sports Competition for Disabled Children and wins prizes. With teachers' guidance, he organizes a camping trip to exercise an independent living among the children with disabilities. He contributed his organizing skill, thus making the program a successful one. His leadership role for the group of children with disabilities from the school is a significant contribution, recognized by the parents and teachers.

Contribution to Myanmar Down Syndrome Association (MDSA)

He is the main and regular volunteer of MDSA. He contributes his time at every MDSA organized social event, celebrations, sport events and fund raising events. He participated in the dance performance at the celebration event of World Down Syndrome Day. In addition, he distributes drinking water bottles and snacks to the people with Down syndrome, families, nurses, teachers and dentists during the dental health screening event. During the event on *Awareness raising education talk on hearing*, he volunteered to clean tables and to put into place at Disabled school for children at Thamaing. He assisted other children with Down syndrome during walking event on the day to celebrate in commemoration of World Down Syndrome Day. He contributed his volunteer service to assist other Autistic children during walking contests and to teachers from other schools. On behalf of people with Down syndrome, he was interviewed in the event of teaching aid donation ceremony to ECDC.

Contribution of National Significance

Aung Lin Htut contributed his skill in performing as an actor of a documentary film projected for awareness of inclusive education in support to Education for All project in Myanmar. In the film, his role was that of a child with Down syndrome who asks for inclusive education in Myanmar.

He is one of the role models among the children with Down syndrome. Moreover, he advocates all the children with intellectual disability to get full participation in the movement of Education for All in Myanmar. With his leadership skill, he encourages other children with Down syndrome enabling to stay independent and to enjoy life without discrimination in the society. Through family support network, Aung Lin Htut provides parents with an opportunity to make friends and to share challenges, milestones and triumphs as they raise their children with Down syndrome.

1. He gives awareness that the people with Down syndrome have their own talents.



2. He gives awareness that people with Down syndrome can emerge their abilities if they get proper support their hobbies and interesting.



3. Aung Lin Htut who gives peer support to reach their goal in the Walking Event



4. Aung Lin Htut who is contributing in the habilitation of Eden School



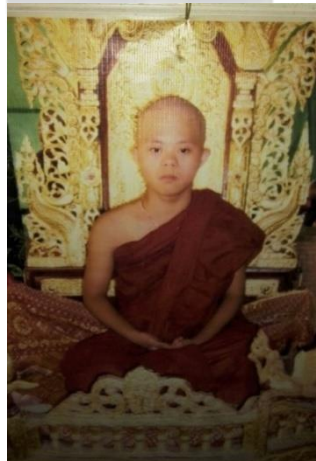
5. Aung Lin Htut's Trophies and Awarded Painting for his creative, artistic and intellectual potential





6 .Aung Lin Htut who is a regular volunteer of Myanmar Down Syndrome Association

7 .Aung Lin Htut's capabilities and contributions in his environment



8 .Aung Lin Htut's Novice Life

9 . Aung Lin Htut's Camping Certificate which is expressed his effort, his mother's nurture and the training of his school



Fighting against All Odds - Khant Yay Kyi

A Grade 2 student, Khant Yay Kyi, 15 years old who entertained the audiences with Thingyan songs on the stage during Myanmar Thingyan festival is a child with Down syndrome. She was born without anus (imperforate anus).

When she was just four days old, she has done colostomy and also there were ASD and VSD in her heart. Again, when she got two years old, PSARP operation was done (imperforate anus which was repaired) and started can pass motion like other children since then. She is not strong enough in motor movements and therefore she is trained for both fine and gross motor skills. Only when she became five years old, she could be able to walk without helpers. Heart closures were done at the age of 13 with the cooperation of the doctors from Myanmar and Vietnam.

She is also under treatment for hypothyroid to maintain her health. After these hard days passed, their parents thought that they had already solved all of her health problems and they were trying to focus on her holistic development. Unfortunately, after this peaceful period, she started show quiet and aggressive and it is hard to see her active life style any more. Her parents got worried when they noticed those changes and consulted with the pediatric and did medical checkup.

From the results, parents accidentally knew that Khant Yay Kyi has been suffered from chronic kidney disease. Her bladder is, of course, a neurogenic bladder. In her country, there is not rich enough experiences to do operation for the prevention of kidney which has complex steps to a child with a lot of internal organs problems like her. So she had had an operation for it in Singapore on 8th...January 2018. The operation took 7 hours and it was done successfully by doing surgical Mitrofanoff creation with bladder augmentation.

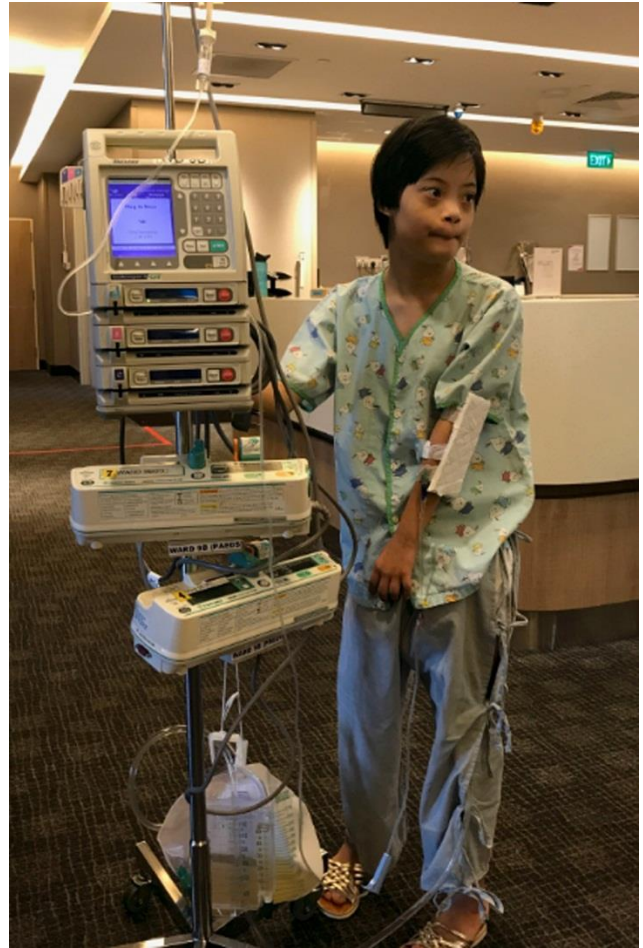
However she needs to take out her urine from the tummy every three hours by using catheter with the help of her mother and nurse. Now she is able to overcome her terrible condition and gets up again in her life by going to school happily and participating in social activities with her family.

She follows the doctors' instructions like drinking water over 3 liters every day, avoiding some foods which are not suitable for her kidney and doing some physical exercises.

Although there are a lot of problems concerning with her health, she never gives up, always put a smile on her face and passing her days happily without any complaints. She shows her positive resilience.







NEW ZEALAND



New Zealand Down Syndrome Association

Dancing his way to Success – Duncan Armstrong

I am Duncan Armstrong, a member of STRIVE, - the NZDSA's Self-Advocacy Leadership Group.

I am a professional dancer, actor and musician from Wellington, New Zealand. In February 2018 I did a solo show at the Auckland Fringe Festival for which I won a Best Performance award.

As a performer with Down syndrome I can help make people with disabilities more visible. Maybe I can inspire others to create.

In 1989, the year I was born, legislation was passed in NZ to allow all children , with or without disabilities, to attend school. Some schools set up special classes, or units, but many chose to include students with disability in their regular classes- that was called 'mainstreaming'.

I am a mainstreamer. I went to my local primary school, then to the local co-ed secondary school. I was always in the classroom with the other students, never in a unit or special class.

At College (secondary school), I studied what everyone did, my favourites were Drama , Music, and Maori performing arts. I loved being in school productions and musicals, and the choir.

After 5 years at secondary school I went on to do a tertiary foundation certificate in rock music at Whitireia Polytechnic. The study was hard but one of the other students was my helper.



I have been playing the drums since I was 10, and perform in a rock band called Mr Handsome. My dad is also in the band. I write songs about my life. I like to share my feelings through song lyrics, as someone else might connect to that same feeling.

I have worked with Touch Compass Dance Company since about 2005 and been a professional dancer with the Company since 2015. One thing that is hard for people with disabilities is getting good professional training - I have taken a lot of workshops to learn and develop my craft.

With Touch Compass I made a short film called *Drumming is Like thunder*. It was an amazing experience to be invited as a guest to the Sydney Film Festival 2017, after winning an award for 'Most Original Film' in the *Sit Down Shut Up and Watch* Festival, South Australia 2016. The Film is now being screened across the USA as part of the *Sprout* Festival.

I have also acted on stage and on TV. I was in the first season of the tv show *Nothing Trivial* (2011). Since then I have been working with Wellington Theatre Company *Everybody Cool Lives Here*. I acted in several shows before writing my own with Isobel MacKinnon. The solo show is called *Force Field* and is about a man looking for love.

I feel proud of what I have achieved so far. In 2010 I won a Young Artist award from Arts Access Aotearoa. In 2017 I won a Highly Commended in the Artistic Achievement awards. Then later in 2017 it was great to receive support from Creative New Zealand to develop *Force Field*, as I think this was the first time an individual grant had been awarded to someone with a learning disability. Winning the Best Performer award for the show at the

Auckland Fringe Festival this year made me feel great and made all the hard work worthwhile.

We hope to take the show to more festivals in NZ and overseas. I am keen to work and perform anywhere in the world.

I would also like to do more training in stage and screen, because there is so much to learn- and I would love to help make training in the arts easier to get, for people with disabilities. We have to do heaps of workshops, wherever we can find them- which is great, but real training with other performers without (and with) disabilities would be Even Better

I am an advocate with STRIVE, working to empower and value young people with Down syndrome, and I see my performing work as an important part of that, making people with disability visible in mainstream culture, and helping us all to respect each other and enjoy our differences.

Edward speaks for himself and Down syndrome

When I was born my Parents told me there not a lot of support for people with Down syndrome or their families. My parents learned to fight for all the support they could get.

Today things are a lot better. I have also learnt to speak up more for my self

My name Edward I have Down Syndrome. I am 38 years old and I live with my parents. My two brothers have both married and left home. One day I hope to leave home too and go flatting. I have been thinking about that for quite a while.

I am proud of my work. I have been working at Pak'n save Supermarket for 16 years. I work out side in the car park collecting and returning Trolleys its fun when the weather is fine but can be difficult when it's wet.

I was in a special class when I went to school. When I got to college I was all so in a special class but I was included in some mainstream classes too.
I enjoy music especially classical & opera. I also enjoy some television.

I am involved in Special Olympics – including Tenpin Bowling; Swimming & Table tennis. one of my highlights was going to Greece for the world summer games & winning a gold medal in the 100 metres back stroke. It was a long way from N.Z. but a great experience.

I am very involved in the Down syndrome association belonging to Strive. This is a Self-Advocacy leadership group. We are a group of 7 advocates from different regions across New Zealand. We are all interested in speaking up for people with Down syndrome. Our mission statement is "WE BELIEVE IN PEOPLE WITH DOWN SYNDROME & VALUE AND PROMOTE THERE VOICE".

What are important to be as a group are our values?

These are;

- Speaking up to be heard
- Teamwork
- Respect
- Inclusion
- Value Individuality
- Empowerment

We strive to make a difference for the lives with people with Down syndrome.

Re Education we believe in inclusion where we get to choose our own school and we include it in the main stream. We believe we have the right to education free from violence, bullying, harassment and abuse. We believe that all students have individual learning needs

a need support to be able to learn and achieve. We recommend training for teachers and I often talk about this to groups of teachers. They seem to find it beneficial and then always listen.

I really enjoy this group because I think we can make a difference for people with Down syndrome. I have made some very good friends and I learn lots from others and we have a lot of fun.

SAUDI ARABIA



Saut - Transforming the Lives of People with Down Syndrome in Saudi Arabia

Saut: The Voice of Down Syndrome Society is a nonprofit organization that aims to empower individuals with Down syndrome in Saudi Arabia through world-class education, training, research and awareness. We have been caring for children with Down syndrome in the Kingdom of Saudi Arabia for almost three decades and in that time we have developed a unique model that has won international recognition.

Under the umbrella of Saut: The Voice of Down Syndrome Society sit the Mohammed bin Naif bin Abdulaziz Schools for Down Syndrome – a network of educational institutions dedicated to teaching children with Down syndrome. No other school in Saudi Arabia serves people with Down syndrome from birth until adulthood, providing for their educational, medical and social needs.

Thanks to constant support from international consultants and links with research centers in the USA, we employ effective and well-researched educational techniques for our students. We place students in classes according to age and not ability. This encourages them to develop behaviors and friendships appropriate to their age group. Meanwhile we meet every child's individual learning needs by creating a tailored curriculum and individualized education plan for each student. The centerpiece of our commitment to making a better life for those with Down syndrome is our vocational program, which has successfully placed many of our graduates in productive and rewarding jobs. By coaching students in the workplace, with visual aids and exercises to help them achieve autonomy in their roles, we are starting to change the attitudes of many employers towards individuals with Down syndrome.

Despite our strong connections with international experts and research centers, we remain very much a Saudi institution. Over 85% of the staff and 98% of the students are Saudi nationals. In addition, all of our curricula and assessment tools are translated into Arabic. Our students are taught useful and relevant skills, including Islamic studies and vocations that apply to the local job market. In this way we ensure that our students become proud and effective citizens of their country.

TURKEY



Down Türkiye
Down Sendromu Derneği

Down Syndrome Association, Turkey

My Voice My Community Project

Down Syndrome Association Turkey runs a self-advocacy project called “My Voice My Community” with the partnership of Down Syndrome International (DSI) and funded by Sabanci Foundation. The project includes preparing a training program for both the educators and people with Down syndrome. The educators of Down Syndrome Association Turkey got a training from DSI experts about running a self-advocacy program with people with Down syndrome.

Self-advocates started to gather every couple of weeks by January 2018. They discussed about self-advocacy, their rights, the things they need, networks and communities, and the topics they want to advocate. With the support of a MP, the group got a chance to make a speech at Turkish Parliament on 21th March World Down Syndrome Day. They decided to talk about what independent living means for them, and what they need in order to achieve it. They run the preparation session all alone, without a support person, for the first time after 2 months.

There was also a press conference before the speech. It was released all mainstream media channels and this was the great opportunity for them to be heard among Turkey.

It is the first time that people with Down syndrome talked for themselves in front of such a big crowd and they made the language shift from mercy to a right based approach.

The preparation session



Press Conference



Speech at the Parliament

