



Contents

President Speaks	3
A Fashion Star in the Making – Vihaan Vyas.....	4
The Upward Journey Begins - Down Syndrome Society of Bangladesh	6
Passang’s Journey- A child with Down Syndrome	9
Eco Bag Project Boosting	11
Uplifting the living standards of the families of members with Down syndrome (DS)	13
Down Syndrome Parents’ Support Group in Thailand - Twenty-Five Years Experience.....	21
Our Activities.....	27
Buddy Walk in Shibuya, Tokyo.....	30
Touching New Milestones.....	35
Down syndrome cannot put me Down – Ms. Kun Naychi Khin	36



ASIA PACIFIC
DOWN SYNDROME
FEDERATION



August 2019

From the President's Desk

President Speaks



One more quarter has passed and after the successes of the World Down Syndrome Day Celebrations 2019, we are back to the regular activities of our respective Federations.

Our regional members have been co-operating amongst themselves to share knowledge and gain insights into methodologies that can assist persons with Down syndrome in our region. A case in point is Pakistan from where the Secretariat received a request for information on Early Intervention. The team from Nepal responded as soon as they received the information and sent the requisite materials across. APDSF is redefining the term “Bonding across Borders “through such initiatives.

I will be meeting a Down syndrome Association in China next week and will keep members updated on this new development in the next edition of our Newsletter.

I am glad that as a body we are able to achieve new milestones and I can see that there are many more coming. Let us all join hands and work towards our goal of making the world an inclusive one.

Regards

N. Ramachandran

India

A Fashion Star in the Making – Vihaan Vyas



Vihaan Vyas (7 years) was selected from among thousands of children to walk the ramp for designer Kirti Rathore at the recently held **India Kids Fashion Week**

It was a small trip to the garden which made his parents realize that he has inclination towards modeling and posing for the camera. At merely 6 years of age, Vihaan was suggesting postures and asking his father to click his pictures.



Earlier this year, Vihaan also auditioned and got selected at the **Master and Miss Delhi contest**, a talent-cum-fashion show. He enthralled the audience with his dance moves on the stage. His style and confidence which captivated the onlookers attention.

Motivated by his performance at the talent show, his mother sent his pictures to India Kids Fashion Week. At the auditions held at The Ambience, Gurgaon he again impressed the judges with his confidence. The father-son duo were also the winners of one of the pre-contests of Best Selfie.

At the finale, Vihaan walked the ramp in a Kirti Rathore collection with 29 other kids. Although his first time on a proper ramp, he walked with poise and a smile. He made an instant connection with the audience as he waved out to them.



All of 7 years, Vihaan dreams of being a successful model one day. His journey has just begun....

Bangladesh



The Upward Journey Begins - Down Syndrome Society of Bangladesh

Down Syndrome Society of Bangladesh (DSSB) is a platform for children and adults with Down syndrome and their parents. The sole purpose of our organization is to inspire children born with Down syndrome by enabling them to help change the world and assist them in special needs advocacy, education, employment and social inclusion.

Down syndrome is a condition, not an illness; it is, rather, a blessing. Children born with an extra chromosome have unique talents that are not acknowledged. DSSB wishes to educate and create awareness about this condition and offer support for parents with children, relatives or friends who have Down syndrome.



Early in 2010, a group of parents of children with Down syndrome recognized that a great need existed in Bangladesh to support and educate families. Out of our understanding initially the Down Syndrome Parents Support Group was formed. In order to raise public awareness, with Japan Bangladesh Friendship Hospital, AMDA Bangladesh, Robi Axiata and other organizations observed the World Down Syndrome Day on 21st March, 2014 for the first time in Bangladesh.

As a self-funding, non-profit organization, we work closely and regularly with health and educational professionals and other voluntary welfare organization. The Society is affiliated to national and international bodies such as the Department of Communication Disorders, University of Dhaka, Down Syndrome International (DSI), UK, the Asia Pacific Down Syndrome Federation (APDSF) and regularly works in collaboration with other Down syndrome organizations worldwide.



Vision

Create an inclusive society for the Down syndrome communities in Bangladesh through sustainable development initiatives in health, education and employment.

Mission

To inspire and assist people with Down syndrome through advocacy, health needs education, employment and social inclusion.



What we do

1. Awareness

- Parents Support Group
- Dance Group
- Self-advocate Group
- Siblings Group
- Down Syndrome Education
- The Down Syndrome Voice.





2. Healthcare

- Early detection
- Health Screening & counseling
- Speech & Language pathology
- Psychological service
- Occupational therapy.

3. Education

- Early intervention
- Inclusive education
- Skill training
- Employment promotion



Bhutan

Passang's Journey- A child with Down Syndrome

Ability Bhutan Society was founded on the recognition that children with disabilities and their parents needed support. It is a platform to empower and assist them through early intervention based on their needs. Children with disabilities have been availing the service from 2012 and many have been transiting to Early Childhood and Care Development Centres and to the mainstream education where Special Education Need (SEN) programmes are available. There are many achievements that a child, parent and ABS have achieved together through the support, love and affection from one another.

Passang Wangmo was enrolled in 2016 at the age of 3 to Ability Bhutan Society and had been availing the services. When she was born, she did not cry and that worried her mother. The doctor told her that Passang has Down Syndrome. "I was really worried that my daughter wouldn't be able to perform the same task like other children and with this disability she would not be considered part of the society." Passang's mother said. She received rehabilitation at the hospital when she was around 1 year old and by age 3, she was enrolled in ABS in the year 2016. When she first came to ABS, she was unaware of the daily skills and couldn't communicate with others. She was shy and had some trouble adjusting with the activities and surrounding.

Slowly, Passang progressed tremendously with the intervention. She learned the alphabets and could identify shapes and colors. She could interact with people, understand them, eat food by herself and go to toilet. "I realized that worrying does not solve or improve my child's condition. It is important to come forward and provide the necessary support to the children. ABS has helped so much and encouraged that my daughter has now improved. Although slowly, she can now perform same daily tasks like other children," mother said. Passang is now enrolled in Changangkha Middle Secondary School, in the mainstream education in class PP where Special Education Needs programmes are included.

By assisting to the child's need and having early intervention can provide platform for children with disabilities to come forward, enhance the development of a child, develop foundation for greater opportunities and empower family. Passang Wangmo's success in

her social life is a pride for Ability Bhutan Society. Likewise, many parents are now coming forward and is aware about the importance of early intervention.



Passang Wangmo

Mongolia

Eco Bag Project Boosting

Last year Down Syndrome Association Mongolia put a start of ECO BAG Project with support of Khaan Insurance LLC. The project involved skilled in sewing mums with children with Down Syndrome.

The recent advancement of the project was brought by WRTogether NPO. In May this year teens with Down Syndrome had fantastic days with volunteers of the NPO enjoying art, crafts and painting. Nice eco bags with their paintings on canvas have been very successful!

Our bags have been sold on Mongolian Spring Festival at Higarigaoka Park in Tokyo. Thank you, WRTogether NPO for every purchase for special kids and their families!

This spring one of the largest chain of supermarkets in Mongolia named SANSAR liked our bags, and now selling them in its supermarkets supporting our project. Thank you very much, indeed!





Sri Lanka

Uplifting the living standards of the families of members with Down syndrome (DS)

Project overview

Jinendhi Resource Centre for Down syndrome (JRCDS) is the only organization that works exclusively for persons with Down syndrome, despite there are many organizations working for persons with intellectual disabilities. Our vision and mission is to introduce and implement a national level programme with the purpose of educating and improving the skills and capacities of persons with DS to contribute to the society and creating a caring community for persons with DS in collaboration with the government, schools and civil society organizations as well as the private sector.

The project, 'Uplifting the living standards of the families of members with Down syndrome (DS)' which will be carried out by JRCDS will support the families of members with Down syndrome to uplift the general living standards of the family and particularly the family member with (DS).

The project will provide loans to the family members who are already engaged in small scale businesses to expand and to improve the quality of their enterprises with finding suitable market opportunities. The project is aimed at improving the wellbeing of the whole family.

Project objective

Persons with DS lead healthy, skilled and secured lives through increased family income

Project outcomes

- Increase in overall family income
- Children with DS receive education and develop their skills
- Children with DS live a healthy and secure lives

Action Plan

#	Activity	Duration
1	Identifying the families who are already engaged in small scale businesses	01 Month
2	Identifying the requirements of the families	15 Days
3	Signing agreements with the funding organization	15 days
4	Providing necessary loans for the families	01 -05 months
5	Developing a monitoring mechanism	15 days
6	Developing action plans to develop the enterprises within an agreed period of time	15 days
7	Home visits and monitoring	Throughout the year
8	Training programs on enterprise development	3 days
9		

Monitoring and Evaluation

Measure	Collection Method	Frequency	Beneficiaries
Children progress in their education	IEPs, M&E tools	Once a month	10 children
Increase in family income	Income data	Once a month	10 children
Children's health is maintained	Medical reports	Quarterly	10 children

Officers from Jinendhi Resource Centre for Down Syndrome carryout the monitoring and provide necessary feedback with relevant authorities.

Implementation

JRCDS will support one family initially as a pilot with the expectation of expanding to other families with members with DS. The following is the action plan of the selected case.

Case 1

A family selected to provide loans has a child of 4 with DS. The mother prepares lunch packets and sells to the staff of a reputed food chain. Her husband is a Grama Niladhari official and they have two other children of 15 and 13 ages. Their income is not sufficient to educate three children and for extra expenses on speech therapy and occupational therapy sessions for the youngest child with DS. The family has already started an enterprise on buying, packing and selling tea leaves. The enterprise is registered under the name of Nava Dimbula Kahata and currently it has come to a standstill as they are short of finances to invest on it.

Once this project is implemented we would proceed with the rest of the families.

Action Plan

#	Activity	Time period	Unit cost	Total cost	Person responsible
1	Identifying the requirement of the family	1 week		0.00	PC
2	Developing the proposal	1 week		0.00	PC/MD
3					PC/MD
	<u>Purchasing</u>				
	Purchasing of equipment Sealer	} 1 week		5,000	
	Purchasing of Polythene and stickers			5,000	
	Purchasing of tea leaves (1kg=Rs700.00)		Rs.700 Per 1kg	700X50 35,000	
	Transportation cost			15,000	
	Total cost			60,000	
	<u>Sales</u>				
	Packets of tea leaves				
	10 pkts of 1kg (10kg)		Rs.1200	1200x10 12,000	
	20 pkts of 500g (10kg)		Rs. 600	600X20 12,000	



	60 pkts of 250g (15kg)		Rs.300	300X60 18,000	
	150 pkts of 100g (15 kg)		Rs.120	18,000	
	Total revenue			60,000	
4	Developing a monitoring mechanism	1week		0.00	PC/MD
5	Monthly monitoring and feedback	3 months		0.00	PC/Funding organization
6	Training programs on enterprise development			0.00	PC/MD
Total budget:				

Monitoring and Evaluation of Case1

Measure	Collection Method	Frequency	Beneficiaries
Completing the purchases within one week of provision of loans	Invoices	One time	The family
Family income increases by 25,000/= Per month	Invoices of buying and selling	monthly	The family
Child with DS receive speech therapy	Verification from the speech therapist	monthly	The family
Child with DS receive occupational therapy	Verification from the occupational therapist	monthly	The family

Other details of the enterprise

Name of the business- Nava Dimbula Kahata

Nature of the business- Packing and selling of tea leaves-

Name of the proprietor – D.G.Ayanthi Chandrika

Address-47/14/A, Wattarantenna Road, Kandy

Market locations- Kandy and Colombo

Organizational Staff

Director General Mr.Galgamuwa will overlook the project and the Coordinator Ms. Charmi Basnayake will carry out implementation and monitoring and evaluation of the project.









Charmi Basnayake who works as a volunteer at Jinendhi Resource Centre for Down Syndrome is following a diploma at National Institute of Education. She is an enthusiast in researching on improving the cognitive as well as socio- emotional skills of children with Down syndrome. She has been working with Jinendhi Resource Centre during the past few months to extend her service more to the community.

Charmi had started visiting families with Down syndrome to assess children and to make educational plans for each child and to render her service to improve their skills as well as to direct the parents to get support from other parties such as teachers, occupational therapists and speech therapists. She has been visiting many schools in Sri Lanka for children with needs to study the teaching methods used in different schools catering the varying needs of children and also she has been teaching in several schools as a part of a requirement of the diploma on special education.

We as an organization working exclusively for persons with Down syndrome developed several proposals along with her contribution. We plan to direct our service to the following areas in Kandy district;

- Persons with DS lead healthy lives
- Infants and children with DS reach their fullest potential in education and skills
- Adolescents aged 15-18 and adults with Down Syndrome are capacitated and empowered to reach their maximum potential
- Community is capacitated in creating a caring society for persons with special needs.
- Future of the persons with DS are sustained and secured

Apart from the above areas we are currently executing art programmes for children with Down syndrome, introduced loan schemes for families with children with Down syndrome, and are planning to train volunteers from each Grama Niladhari division to visit houses with persons with Down syndrome, assess them and direct them to necessary services. Another project we have developed is to develop the capacity of pre-school teachers and to create a child friendly environment in pre-schools lead by the Municipality Council in Kandy District.

We hope to expand the our services to other districts in Sri Lanka in the coming years to make the lives of persons with Down syndrome better and we Jinendhi Resource Centre for Down syndrome look forward to it.

Thailand

Down Syndrome Parents' Support Group in Thailand - Twenty-Five Years Experience

Pornswan Wasant, Professor Emeritus, Faculty of Medicine Siriraj Hospital, Mahidol University, Bangkok Thailand

Down Syndrome (DS) is a genetic disorder caused by extra copy of chromosome 21 resulting in delayed development/mental retardation, congenital heart disease, congenital hypothyroidism, gastrointestinal anomalies, etc. It is a common disorder with incidence of 1: 800 live births. Shock and grief occurs when physician inform parents of their infant's diagnosis and prognosis. Twenty years ago infants with DS were abandoned (almost every month) at Siriraj Hospital (the largest hospital in Thailand, 2500 bed capacity) due to lack of education among doctors, nurses and parents. Therefore, Educational Program for parents of DS children, medical professionals and teachers was established at Siriraj Hospital in Bangkok since 1987.

Its aims are to achieve a composite set of integrated goals which can be outlined as follows:

- (i) to educate parents of children with DS to raise their children to reach their maximum potentials
- (ii) to share experiences of having children with special needs and to provide emotional support by means of breaking the parents' isolation and to help children in difficult situations, especially in the provinces
- (iii) to raise awareness among the government and the general public towards a better understanding and greater social acceptance/incorporation, simultaneously also to provide an appropriate knowledge and to disseminate up-to-date information about the children with special needs in general and the children with DS in particular
- (iv) to empower parents of children with DS to voice their demands and basic rights in education/schooling, health care and vocational pursuits.

In the course of 25 years the Support Group has employed certain practical and viable means within their capacities to accomplish the above goals. Particular efforts have been invested in its competent fields of activities which can be highlighted as follow:

- (i) having produced educational materials, e.g. pamphlets, newsletters and videos for educational purposes among medical professionals, nursing/education personnel as well as the public.

- (ii) having provided counseling and emotional support in time of crises, especially at the time of birth of a baby with DS which could bring grief and tremendous emotional shock to people concerned. Additionally the early stimulation programs tailoring for DS babies and children are available and sustained throughout.

(iii) having run 'Down Syndrome Annual Meeting' at Siriraj Hospital on a regular basis since 1991.

(iv) having organized 'Down Syndrome Annual Provincial Lecture Tour' (nicknamed 'Down San-jorn') in collaboration with hospitals and health institutions in the provinces outside Bangkok; since 1997, sixteen tours have been launched.

(v) having worked closely with the Department of Maternal & Child Health, Ministry of Public Health since 1991. As an accomplished outcome, the proposal of establishing "Child Development Center" for the improvement of quality of life of children with DS in every province in the country has been accepted and become materialized. One main aim is to educate the public health professionals to establish a Child Development Center at the community level, so parents of children with DS will be able to help their children in their respective localities.

(vi) having joined other disabilities group (autism, visual impairment, hearing impairment, cerebral palsy and others from 1994-1999); demanding for basic rights to education, jobs and social participation and finally the Educational Act of 1999 (following the Disability Act of 1991) was passed by Thai government.

Some of these efforts could be regarded as proud success. However being far from having realized all the objectives, undoubtedly there are much works to be done, and sustained support very much sought.

Down Syndrome Parents' Support Group established since 1993



Counseling, Genetics Clinic





Preparation for Kindergarten



Multidisciplinary Approach



Developmental assessment



Hearing assessment



Visual assessment



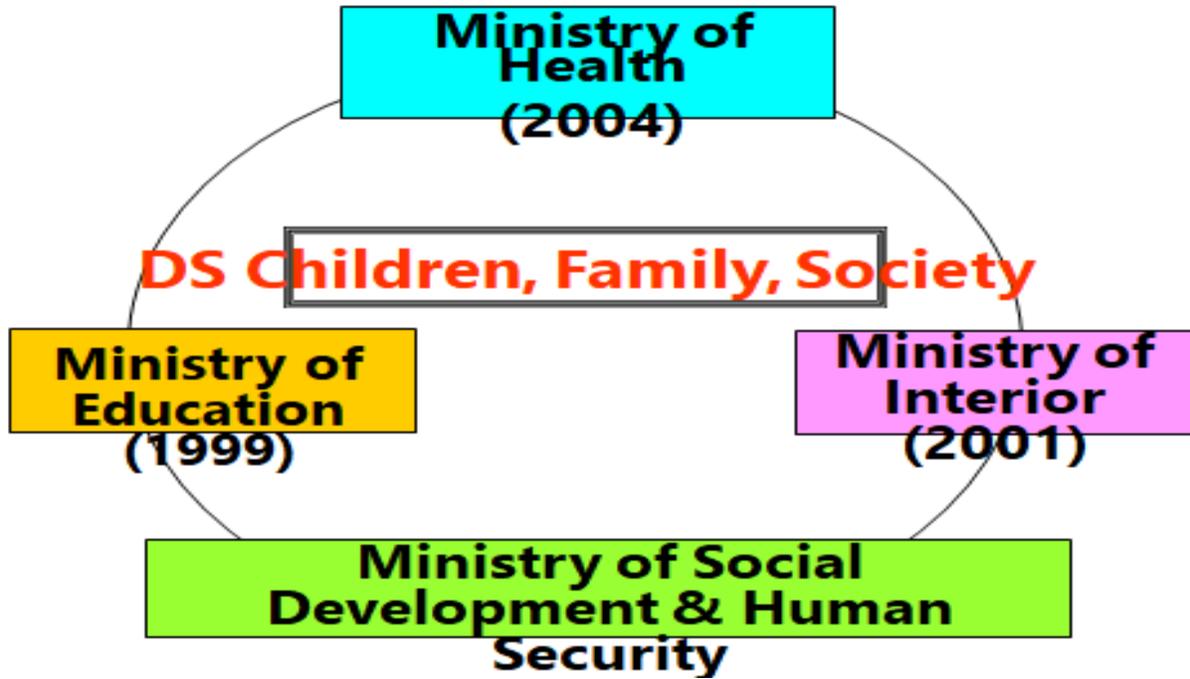
Intelligence assessment

**Educational Program for parents and medical professionals
Siriraj Hospital Down Syndrome Annual Meeting (since 1991)**



Down Syndrome Provincial Lecture Tour (since 1997)





When a **DOWN** becomes a **STAR**



Australia

Our Activities

Down Syndrome Australia (DSA) has had a very busy year working on behalf of people with Down syndrome and their families in Australia. Our three main priorities this year have been in advocacy, resource development and the promotion of self-advocacy amongst our community.

Advocacy

Federal election: Australia went to the polls for a Federal Election in May this year and DSA seized the opportunity for Members of Parliament and candidates to hear from people with Down syndrome and their families. We distributed a range of election resources including our key resource, *Leave No One Behind*, which articulated the important election issues for people with Down syndrome and their families. It was [available in Easy Read](#) as well.

DSA also released an [advocacy guide](#) to support people with Down syndrome to communicate with Members of Parliament and local candidates.

Prenatal testing: There is debate in Australia over whether Non-invasive prenatal screening (NIPS) will be added to the Prescription Benefits Scheme. "The technology that enables genetic screening is rapidly advancing and becoming more widely available. But families who participate in pre-natal screening often don't get all the information they need and don't have access to suitable counselling before and after screening," according to DSA chief executive Dr Ellen Skladzien.

DSA launched a petition in response to this which calls for:

- better guidelines for genetic screening
- a national training program for health professionals who deliver screening services
- more information about the conditions that are being tested for and the accuracy of these tests
- better access to counselling before and after screening
- a public awareness campaign to tackle the stigma associated with intellectual disability

Over 1,500 people have signed the Down Syndrome Australia petition for a co-ordinated, national approach to pre-natal testing. [Please sign the petition.](#)

Migration

The Australian government currently places restrictions on visa applicants and their family members who have a disability or a health condition which the government deems likely to be a

'significant cost' to the Australian community and can do so due to an exemption under the Disability Discrimination Act. DSA is deeply concerned by these restrictions and believes they are unwarranted.

DSA has been advocating the Australian government to:

- Amend the DDA to remove the exemption of the Migration Act 1958 from its scope
- Adhere fully to all provisions of the UNCRPD
- Look to what is happening overseas such as the recent changes implemented by the Canadian government to their migration health and disability requirements.

DSA has also been advocating in certain individual cases such as the case of a young baby with Down syndrome and leukaemia who faced being left without parents to care for him in Australia after his mother's carer's visa was denied and she faced deportation back to China.

National Disability Insurance Scheme

The NDIS is a major change in the way disability services are provided in Australia. For most people with Down syndrome the roll-out of the NDIS has led to better access to services and supports. Unfortunately, this is not the case for everyone.

DSA surveyed our community in 2018 and identified key issues:

- Families spending significant amounts of money to get specialist reports to prove eligibility for NDIS.
- NDIS representatives in the planning meeting having a poor understanding of Down syndrome.
- Incorrect information about what services could be included or being told they need to use segregated services.
- Difficulty getting access to services needed to implement the plan.

DSA has been working with the NDIA to improve the understanding of Down syndrome among planners and improving the pathway into the scheme for participants. We have also been advocating to make Down syndrome automatically eligible for support under the scheme which currently it is not.

Self-advocacy: The Down Syndrome Advisory Network

The Down Syndrome Advisory Network is a group of people with Down syndrome from across the country who meet monthly to give feedback and input into the work that DSA does. This includes input into the development of resources and direction on the advocacy needs of the community. DSAN was instrumental in the development of our Election Advocacy Platform and worked with us to develop a series of videos articulating their views on key election issues. You can see them at our *Youtube Channel* with #leavenoonebehind

Members of DSAN also contribute to *our national journal Voice by* writing a wrap-up of the work members have been involved in.

The DSAN Chair Michael Sullivan's article for the April issue was a particular highlight. You can read it here: <https://downsyndromevoice.org.au/april-2019/2019/3/17/dsan-update-april-2019>

Information

DSA recently published three new resources for people with Down syndrome and their families as well as an animation to promote inclusion to young children.

Down syndrome and Mental Health provides information and tips to maintain good mental health. The publication also helps people with Down syndrome and their families identify when professional support might be required

Supported decision making and Down syndrome explains why supported decision-making is important and how to make it happen. This publication provides suggestions and advice on how to support people with Down syndrome to be involved in decision-making.

Our *Practical Guide to Ageing Well* is for people with Down syndrome and the people who support them in their daily lives. This guide contains general information about ageing with Down syndrome and information to help you plan for ageing well.

We're all different and that's super great! - This animation is based on characters drawn by an artist with Down syndrome Nathan Gooley and developed to promote inclusion among school aged children.

This animation was added to the *Community Inclusion Toolkit* - a suite of resources developed by DSA promoting inclusion for people with Down syndrome in employment, education, health and community groups. The toolkit includes a range of resources such as fact sheets, power point presentations, videos and case studies.

The toolkit is one part of our *comprehensive online resources section* which is free for anyone to access and download. A selection of our Information for Life resources have also been *translated in to five languages*.

Japan

Buddy Walk in Shibuya, Tokyo

Acceptions, a newly established Down syndrome parent group organized a Buddy Walk in Shibuya, Tokyo on the 31st of March 2019. The Buddy Walk was held for the purpose of awareness about Down syndrome and persons with Down syndrome. People with Down syndrome and supporters enjoyed walking Shibuya Scrumble-Crossing, which is a famous tourist mecca in Tokyo.

For more information, click on the link <https://www.47news.jp/3421646.html>



BUDDY WALK TOKYO 2019









The 2nd Congress of Down syndrome in Tokyo

The 2nd Congress of Down syndrome in Tokyo, November 16th and 17th, 2019

<http://jcds.jpn.org/jcds2019/>

Japan Down Syndrome Association and the society of Down Syndrome (nationwide study group) will hold the Congress of Down Syndrome this year. The congress was established in 2017. The purpose of the Congress is to share the update information and research on Down syndrome and to promote the study on Down syndrome. Participants are from wide range of field; medical practitioners and researchers (doctors, nurses, physical therapist, speech therapist, clinical psychologist, medical researcher, medical outreach practitioners, etc) education practitioners (school teachers, counselors, coordinators from elementary school, junior high school and high school), nursery practitioners, social workers, job consultants and supporters(job coach, job support organizer, companies etc).

In the congress, four themes are studied with participants ; 1. study, 2. life, 3. entertainment, 4. work and employment. Academic Symposium on NIPT is organized as well. If you are interested in the congress, please contact jcds2019@k-con.co.jp

**THE 2ND JAPAN DOWN SYNDROME
CONFERENCE**
2019/11/16, 17
Application starts from 10:00 am on July 1, 2019

OUTLINE OF THE EVENT SCHEDULE, PROGRAM PRE-REGISTRATION

Privacy Terms

第2回 日本ダウン症会議
Japan Congress of Down Syndrome 2019

Indonesia

Touching New Milestones

To date our organization has reached huge milestones especially for DS in Indonesia which includes the following:

- Starting on 16th January 2019, 4 persons w/DS from our Center of Hope ISDI will be working at a prestigious law office, Makarim & Taira S. Law and Consultant Office on a year long contract.....complete with monthly salary, other benefits and best of all showered with love and respect.
- Then on 22nd of July we started sending two students to the Garuda Indonesia Airline airport terminal 3 platinum lounge to welcome, serve and assist passengers prior to their flights. The contract will be for every three months.
- Not to be forgotten or setting aside...is the fact that we are able to sell our bakery products not based on pity, our products are legit...😊 and delicious...and it is spreading and people are buying from us.
- People take notice of our students...and their talents and being appreciated and respected. People are giving us chances to do amazing things. They begin to trust us.
- Fashion and photo modelling for companies.
- On sports...we are the first in Indonesia and maybe the world to open a group for karate with our children earning the green belt too.
- We also are the first in Indonesia and or the world to open a group for bowling.
- Our collaboration with the British Jakarta School still ongoing since 2004 on sports event such as the annual Biathlon and Road Race....with increasing quotas.
- Dental care still continues since 2004 with the Family Dentistry Clinic where we get free annual dental check up and treatment.

We are very proud of our achievements to say the least. Our students have grown well in confidence, self-esteem, happiness, and they are being appreciated and respected for their achievements and not their disabilities.

Praise God and thank God. And we do thank everyone for sending and wishing us well through the years to stay on par with our mission and vision. Without you all...we would not be where we are today.

Myanmar

Down syndrome cannot put me Down – Ms. Kun Naychi Khin



This story is my elder daughter Kun Naychi Khin. She is 16 years old and was diagnosed as a Person with Down Syndrome. When she was born she was a pre mature baby. In Myanmar there was very less awareness about Persons with Down syndrome in 2003. She was my first child and I was 23 years old. Doctors and pediatricians said that she has Down syndrome and may or may not be able to learn anything. Those few words disappointed me and my husband. I felt like me and my daughter was thrown into the sea. There was no start or end in sight. I felt that I had lost my way.

She didn't have proper early intervention programs and therapy. She could not stand by herself till 2 .8 years. When she was 4 years old, she has a chance to visit the United Kingdom and met with a therapist from Down Syndrome Association UK .

When I came back ,I found a preschool in our city Yangon. There was no preschool which accepted her because she could say only a few words while communicating and did not have the balance to climb. At that time there was one Special needs school (New World therapeutic Center) that opened in Myanmar. She attended this school for two years. After that she attended Lighthouse learning center from 2009 in their early intervention programs. Now in 2019 she is in junior class.



In 2011 when she was 8 years old she joined Special Olympics Myanmar and participated in the National Games in 100 meters walk and won the 2nd prize. She participated in the 200 meters race and won 2nd prize. I am proud to say that she is the only Person with Down syndrome in Myanmar to achieve this feat. She attended swimming class and was the source of awareness among the public through an article in the Frontiers magazine. She not only participates in sports but is also learning dance. She has been performing every year at the Prom and World Down Syndrome day celebrations since 2015. She also participates in dance competitions with her friends.

Now she is undertaking pre vocational training from her school and trying to get a Job when she turns 18 years. She lives her life with pride and with confidence because she has a wonderful set of friends and an active social life.

-Ms.Myo Pa Pa