



AUGUST 2024

Contents

FROM THE PRESIDENT’S DESK	3
AUSTRALIA	4
BANGLADESH.....	5
BHUTAN	8
CHINA.....	10
INDIA.....	13
JAPAN	16
MALAYSIA	18
MONGOLIA	20
MYANMAR.....	22
NEPAL.....	24
PAKISTAN.....	26
PHILIPPINES.....	28
SRI LANKA.....	34
TAIWAN	38

FROM THE PRESIDENT'S DESK



It is time for yet another edition of the APDSF e-News. When we started, we thought of it as a means of connecting with the region, but now it has become a storehouse of information from all our member countries. This is a remarkable achievement in itself.

As President of the Asia Pacific Down Syndrome Federation (APDSF), I am looking forward to our Annual General Meeting (AGM) scheduled for December 5-8, 2024, at the Hotel Mercure Shaw Parade in Kuala Lumpur. This year's AGM promises to be a significant event, gathering advocates, professionals, and families from across the region to discuss progress and future initiatives.

We are witnessing a transformative shift in the recognition and inclusion of individuals with Down syndrome. This progress reflects a broader societal change toward understanding and acceptance. At APDSF, we are committed to driving this momentum forward, working to ensure that individuals with Down syndrome are not only acknowledged but embraced in all facets of society. Our role is crucial in fostering an inclusive world where every person can thrive. I look forward to engaging with all of you in Kuala Lumpur as we continue this vital journey together.

N. Ramachandran

President
APDSF

AUSTRALIA

We are still buzzing from the incredible World Down Syndrome Congress 2024 we hosted in Brisbane last month. Over four memorable days, nearly 1,000 delegates came together to learn, celebrate, connect and drive positive change for our community.

Hosting Congress is a standout moment in DSA's history and the result of three years of hard work. A heartfelt thank you to everyone who attended and to all who made this event possible: our dedicated patrons, committee, staff, volunteers, sponsors, speakers and special guests.

For more detailed stories, including interviews with some inspiring Congress speakers, look out for our special Congress edition of Voice in October. Also, stay tuned for a series of educational videos shot at Congress in the coming months. These will feature experts, self-advocates and families discussing topics like education, health, employment and self-advocacy.

Although Congress has wrapped up, our advocacy work continues. We addressed the newly released findings of the Disability Royal Commission and have been active in new legislation for Australia National Disability Insurance Scheme (NDIS). We have also been active in participating in a Report on the Department of Home Affairs Review of Australia's Migration Health Requirement (MHR), which unfortunately falls short of what is needed for people with disability.

Congress video: <https://www.facebook.com/watch/?v=1208362173525451>

Article on Congress: <https://www.downsyndrome.org.au/blog/2024/08/01/world-down-syndrome-congress-2024/> Article on Congress: <https://www.downsyndrome.org.au/blog/2024/08/01/world-down-syndrome-congress-2024/>

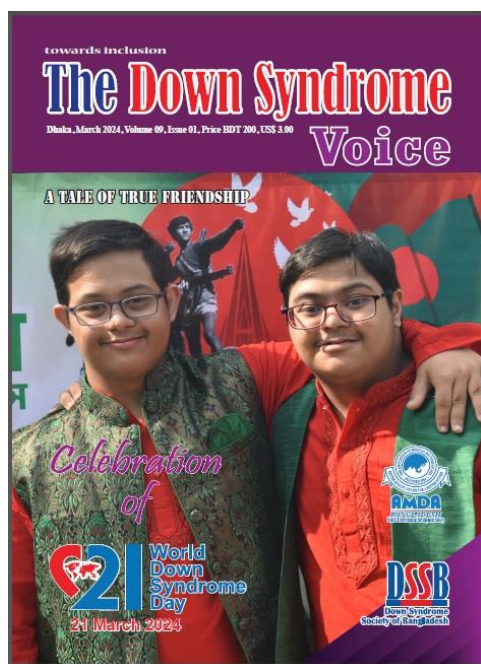
BANGLADESH

We're the national voice for Down syndrome

Down Syndrome Society of Bangladesh is a platform for children born with Down syndrome and their parents. The sole purpose of this platform 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.

Over the years DSSB has been carrying out diversified activities for children and adult with Down syndrome through its Resource Centers. In addition to the regular activities the following remarkable activities were performed during the quarter.

The Down Syndrome Voice Magazine published and unwrapped



DSSB and AMDA regularly publish 'The Down Syndrome Voice' in twice in a year. This year the 9th edition of 'The Down Syndrome Voice' has been published and unwrapped in May, 2024. The next publication will be in October, 2024



Building Effective Networks (BEN)

DSSB actively participated in a 3-day-long workshop from 27th to 29th May 2024 organized by CDD (Center for Disability in Development). The objectives of the meeting are defining the goal and key activities of the 5 year multi-annual program.



The 'Building Effective Networks (BEN)' is a strategic partnership model of Liliane Fonds (LF). BEN applies a community-based rehabilitation (CBR) approach to ensure that the different individuals and institutions around the world are working together to ensure that children and youth with disabilities are able to access and enjoy their rights.

DSSB participation in a 'Caregiver training for life-long care of children/individuals with NDD characteristics'

A three-day long Caregiver Training Workshop organized by Neuro Developmental Disability Protection Trust, Ministry of Social Welfare was held at NDD Protection Trust office from Sunday 29th June 2024. A total of fourteen parents participated in two batches under the leadership of Shahnaz Parveen Chowdhury, Director of Down Syndrome Society of Bangladesh. It was a very effective training session for the parents of DSSB.





Context Analysis on people with Down Syndrome in Bangladesh

Centre for Disability in Development (CDD) organized a day long round table discussion dated on 8th July 2024 aiming to disseminate findings of context analysis on Children with Down Syndrome in Bangladesh - under Child Empowerment Program supported by Liliane Fonds. DSSB experts actively participated as panelists in

this discussion based on the findings of a context analysis conducted by CDD and Liliane Fonds, which identifies policy gaps, perceptions, and institutional barriers faced by children with Down syndrome in Bangladesh. <https://www.dhakatribune.com/351595>



Student's movement and political unrests in Bangladesh

In the middle of July, 2024 political unrest exist in Bangladesh due to massive student movement resulting reformation of an interim government. Still the overall political situation is not in good shape. Due to this unprecedented situation DSSB team was unable to participate in IIDSC-2024 at Kolkata, India.

BHUTAN

Ability Bhutan Society (ABS), Thimphu, Bhutan

**CELEBRATES The World Down Syndrome Day (WDSD) on 21 March 2024:
Along the theme "End the Stereotypes"**



Ability Bhutan Society (ABS) as an active member of the APDSF observes the WDSD every year by way of organizing a day long get-together, dedicated to the individuals with Down syndrome, including their parents, caregivers, family members, well-wishers and the staff of ABS. Wearing colorful dresses on this day and the practice of Rock Your Socks by putting bright mismatched socks in support of the persons with down syndrome has been the culture of our celebration every year.



A parent of a child with Down Syndrome sharing his experiences in up-bringing the child

As always, ABS joined the rest of the world in observing day, along with the theme for the year 2024 "End the Stereotypes", aimed at enhancing the public awareness of the difficulties that individuals with Down syndrome encounter, as a result of misconceptions, stigma and discrimination. The day long program at the ABS intervention center, began with a welcome remark on the importance of World Down Syndrome Day by the Executive Director of ABS, and cake-cutting, followed by

experience sharing by a parent of a child with Down syndrome in up-bringing the child, including an interactive play of indoor games, among others.



Cake Cutting Ceremony to mark the day!



Children with Down Syndrome into ballon bursting game

The observance of the day was supported by the ABS/BMZ/DAHW Asia Project "Engaging and Empowering Persons with Disabilities in Bhutan."

Parents and staff of ABS into ballon bursting competition show-casing their blindfolded talents.



CHINA

Up for Down's Shanghai China

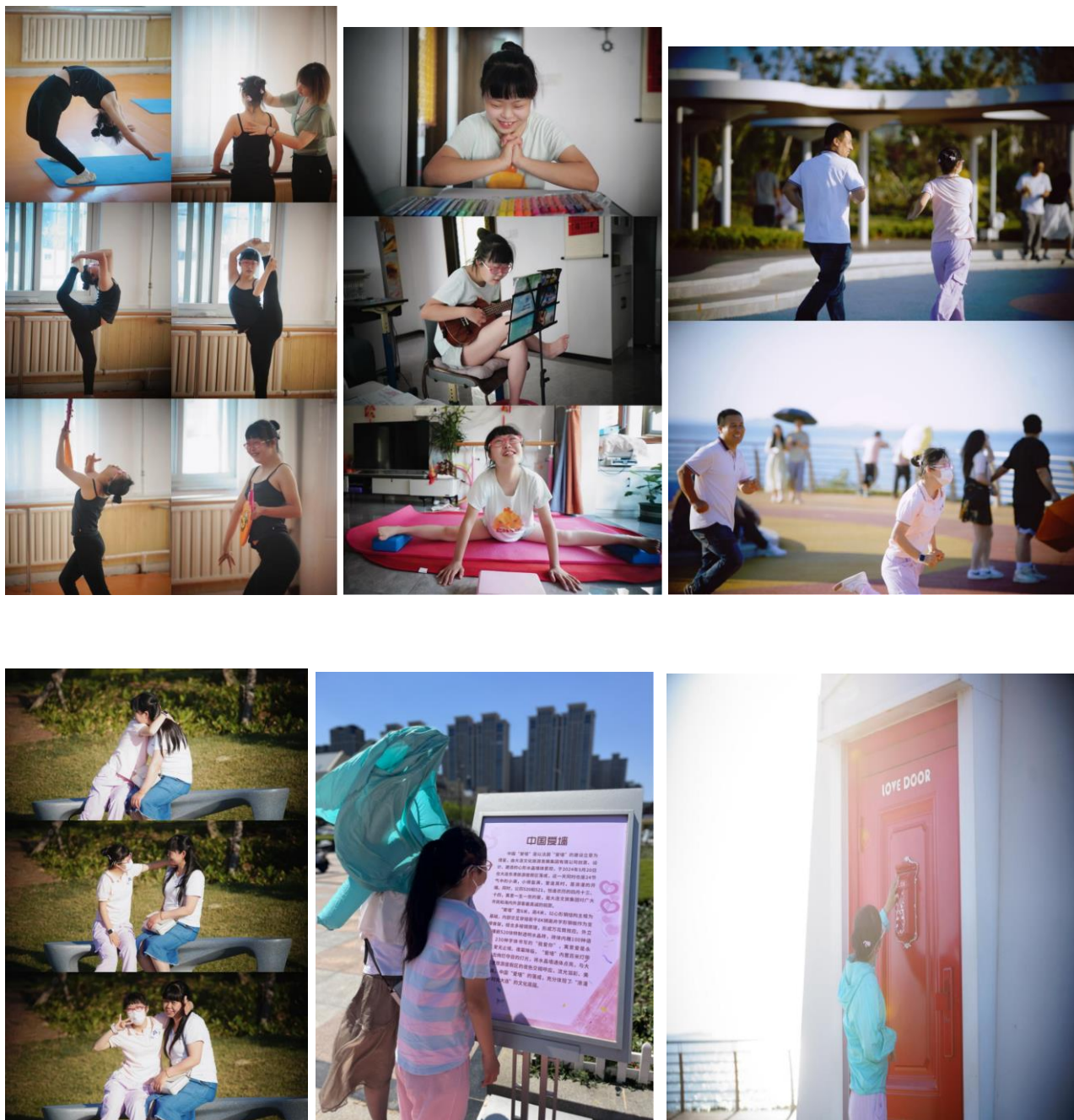
Recently, we have two important things to share with our APDSF members:

1. Volunteer Mary went to Xinxin's home in Dalian for two days interview, and recorded Xinxin's real life to share with every Down Syndrome family. Xinxin is a 16-year-old girl who loves dancing, music and painting. She is a girl who secretly makes cards for her father on Father's Day, and helps her mother shade from the burning sun. Xinxin's family is very kind and friendly.

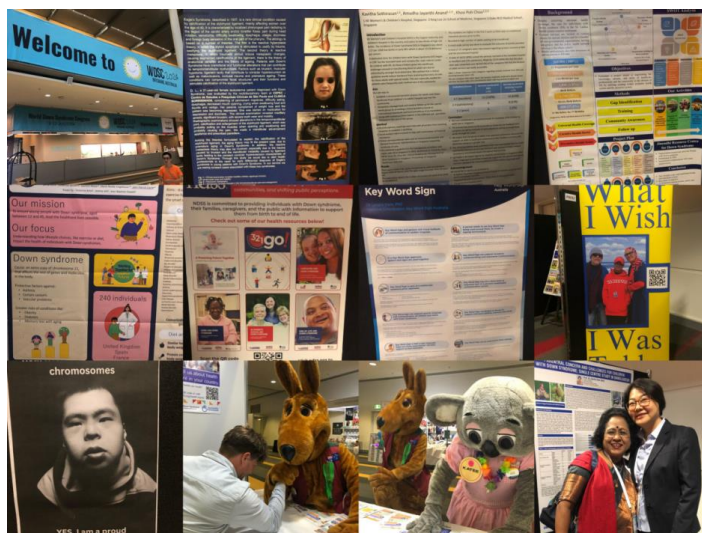
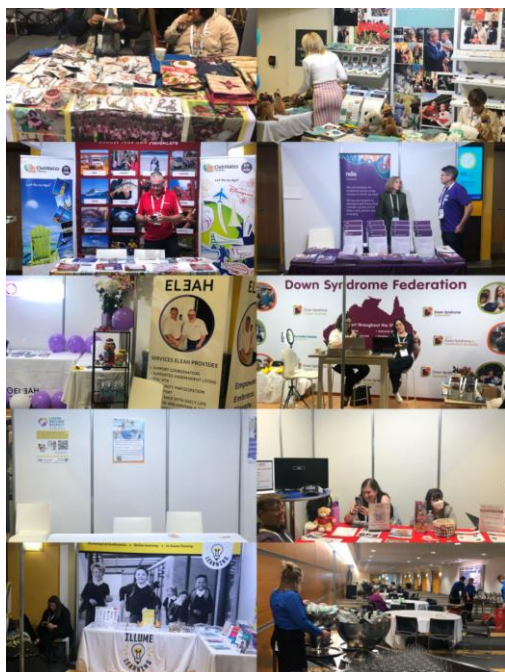
2. Ms. Ye Lei, the founder of Up for Downs, went to Brisbane, Australia from July 10 to 12 to attend the 15th World Down's Congress, to learn how the World Down's Congress is held. Ye Lei found that there were no other Chinese representatives to participate in the congress , and decided that U.F.D. will participate in every World Down Syndrome Congress in the future, and hoped that in the future China can also have the opportunity to host the WDSC with the support of the government.

Part1: Two days interview with Xinxin's family .





Part2: Some photos from the World Down Syndrome Congress



INDIA

The Down Syndrome Federation of India (DSFI) has made significant strides in recent months, enhancing support and awareness for individuals with Down syndrome across the country.

In April, DSFI organized a rejuvenating meet for mothers of individuals with Down syndrome in Ahmedabad. This annual event provided a valuable platform for these mothers to connect, share experiences, and return empowered. At Ahmedabad, the mothers also had an opportunity to interact with the local moms who were thrilled to meet up and share experiences.



May saw the opening of a new chapter in Pollachi, Tamil Nadu, where local mothers came together to bolster support and awareness for families in this interior region. This expansion reflects DSFI's commitment to reaching underserved areas.



July marked a milestone with a successful medical camp in Dibrugarh, North East India, where over 80 individuals with Down syndrome and their caregivers received medical guidance and counseling from Dr. Surekha Ramachandran, DSFI President. The event fostered the formation of an active Parent Support Group in the region.



In August, Dr. Ramachandran addressed cardiologists in Tirupati, sharing the profound experiences of mothers raising children with Down syndrome. Her heartfelt speech deeply moved the audience, leading many doctors to offer their support and services.

The Zoom meetings have been a regular since Covid and continue to be a guidance point for parents of persons with Down syndrome with experts from various fields providing the much-needed inputs to clarify doubts and ease any discomfort.



Art based therapies for our self-advocates



Story Time with Shivani Aunty
6 views • Streamed 6 days ago



Diet is important for our self-advocates - Parini Delhivala



Art as a mode of communication - Dr. Esther Joosa

Looking ahead, DSFI is preparing for the annual India International Down Syndrome Conference (IIDSC) in Kolkata, with invitations extended to prominent figures, including Mr. Subhanjan Das, IAS, to be the Chief Guest.



JAPAN

We presented the Japan Down Syndrome Conference in the poster session of WDSC 2024 July 9-12 at Brisbane, as below. The delegates of the conference consisted of more than 1,000 persons from 45 countries.

We have organized the biennial Japan Down Syndrome Conference since 2017. This conference aims to deepen mutual understanding through the participation of researchers, supporters, care-givers, families, and persons with Down syndrome (DS), in order to create a society in which persons with DS can live comfortably. The first and 2nd conferences were held in Tokyo in-person. The 3rd congress was held online jointly with the other academic societies. The 4th conference was held in-person at Osaka area jointly with the Japan Down Syndrome Association, as in Table.

	Date	Chairman	Num.	Location
1st	Nov 11-12, 2017	Kunio Tamai	400	Taisho University
2nd	Nov 16-17, 2019	Atsushi Kanno	500	National Olympics Memorial Youth Center
3rd	Nov 12-14, 2021	Hirofumi Ohashi	600	WEB only
4th	Nov 11-12, 2023	Hiroshi Tamai	400	Kadoma Civic Center



The followings are discussed in the conferences.

Experts and persons with DS were presented in the fields of 'Health', 'Labor', 'Education', 'Childcare', and 'Advocacy' in the 1st conference.

We have discussed on life-stages of persons with DS, and on functions with 'Enjoy', 'Learn', 'Work', and 'Live' in the 2nd conference.

KeyWords:

Enjoy: Performance in 'Dance and Art', etc. Learn: Primary ~ junior, junior-high School

Work: Employment support programs for disabled in the government or nongovernment

Live: With family, Group homes, Nursing-care facilities

Persons with DS have orally presented their opinions and daily lives.

New medical aspects on the regression disorder in young adults, as well as other immunological disorders were also reported, following much attention have been attracted in the new treatment.

KeyWords:

Acute regression disorder, Alzheimer's dementia

Researchers and care-givers had a discussion about new approaches to elderly persons with DS who have decreased cognitive functions. Families and care-givers have taken home some good ideas.

The Non-invasive prenatal testing (NIPT) is introduced 2013 in Japan. Although NIPT is not definitive, but its convenience mislead to understanding the diagnostic test. Moreover, business-like clinics appear to be exploiting pregnant women's fears. So, discussion on the prenatal testing are active on the national board. Just 10% of the pregnant women in Japan have accepted the test, but slowly spread of NIPT is observed. The specialized genetic counseling should be needed, and this issue is discussed in the symposium.

A lecture or performance are open to the public at every conference. The Japanese conte and rakugo by people with DS were fun and nice.

The kickoff event for celebrating World Down Syndrome Day has been held every year on February. The Diversity is the campaign theme in Japan this year, which is related to 'End the Stereotypes'.

Our conference raised a slogan at each meeting and it was 'Let's take to the town' at the 2023 conference. This is in line with DSI's campaign theme, 'End the Stereotypes'.

MALAYSIA

Welcome to PSDM Pulse!

As we mark 25 years of service to the Down Syndrome community, PSDM Pulse is born from our enduring vision of inclusion and empowerment. This newsletter is your gateway to the latest updates, achievements, and insights from PSDM.

Our journey has always been about creating a nurturing space for individuals with Down Syndrome in Malaysia, and with PSDM Pulse, we reaffirm our commitment to building a supportive and informed community.

Shining Stars

Honoring Exceptional Mothers: Anugerah Ibu Kiwanis 2024



Kiwanis Malaysia District hosted the Anugerah Ibu Kiwanis award ceremony, with the distinguished presence of His Royal Highness, the Sultan of Selangor, and Her Royal Highness, Tengku Permaisuri Hajah Norashikin. The award, revived in 2024 after a decade-long pause, was presented to Madam Hanizan Hussin, President of PSDM. This marks her second recognition, following her first award in 2002.



20 April 2024

Courtyard by Marriot, Setia Alam

Spotlight Programs

January to June 2024

13 - 14 January 2024

Learning Technique Training Workshop 2024: Early Childhood & Teenage Education Program for Children with Down Syndrome



23 April 2024

Hari Raya Celebration by PSDM with Great Eastern



23 June 2024

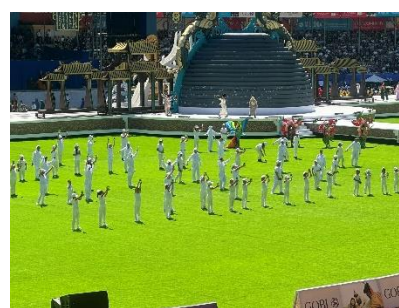
CSR Invitation to NATYAMELA 7.0 Program Organized by BARATHAM University Malaysia Terengganu Cultural Club



MONGOLIA

Greetings from the Down Syndrome Association of Mongolia. We've been enjoying the sunny summer and are now preparing for the upcoming autumn and winter seasons. Over the past few months, our leadership has undergone some changes. We are delighted to introduce our newly elected Chairwoman, Khulan Odgerel /Dsamongolia01@gmail.com/, and our new CEO, Uyanga Choilsuren.

We are proud to highlight that, for the very first time, around 10 Mongolian individuals with Down syndrome had the opportunity to perform during the opening of the Naadam Festival, our nation's cherished holiday. Moreover, two individuals were invited to model Gobi Cashmere's Naadam collection. This was a significant contribution to creating a more accessible and equal society.



In middle of the July, in cooperation with YMCA Mongolia, we organized a successful basketball training session. The training was led by enthusiastic volunteers and facilitated by Fusum Chau from YMCA of Hong Kong. It was truly wonderful to witness how sports can bring people together.



The "Happy Together" project, organized by DSAM volunteers Tuguldur and Nyamsuren, provided our individuals with Down syndrome the chance to engage in various activities such as cooking Latin American meals, dancing hip hop, drawing pictures, and enjoying quality time with caregivers. It was truly a time of joy and togetherness.



MYANMAR

Unwavering Commitment of MDSA and Its Supporters

The Myanmar Down Syndrome Association (MDSA) remains committed to empowering individuals with Down syndrome and supporting their families through various initiatives.

Every Saturday, International Dance Practice brings together individuals with Down syndrome (PWDS) and volunteers, fostering friendships and enhancing motivation. Alongside, Role Play Practice sessions help participants build communication skills, while calming Yoga sessions promote mental and physical well-being.



Guardians, vital to Down syndrome community, gain a creative and therapeutic outlet through weekly Clay Therapy sessions. Bimonthly, MDSA organizes Water Therapy to improve physical coordination and relaxation.



MDSA also prioritizes health with Body Mass Index (BMI) services, Hepatitis vaccinations, and annual Seasonal Flu vaccines, ensuring the safety and well-being of our community. In collaboration with a local dental clinic, MDSA provides free oral health checkups including minor treatments and cleanings, essential for maintaining good hygiene.



A key initiative, the “Yes, We Can” team, focuses on providing meaningful employment opportunities, fostering greater independence and inclusion for PWDS



The Myanmar Down Syndrome Association (MDSA) is steadfast in its mission to support and uplift individuals with Down syndrome and their families, especially during these challenging times. Mirroring the resilience of the traditional Myanmar toy 'Pyit Tai Htaung,' MDSA continues to thrive through the steadfast cooperation of supporters who align with MDSA's core values. Together, we ensure that our community remains strong, resilient, and full of hope.

NEPAL

DSSHA – Nepal is slowly but steadily moving towards its AIM to improve and give parents the knowledge to care for and support their child with Down syndrome and also make children independent and live their life with dignity



Caregiver/Parents training was conducted in two batches 29,30,31 June and 5.6.7, July 2024 to care for and keep their child with DS healthy. Specialists in Genetics, Endocrinology, Dental, Ophthalmology, Orthopedics, Clinical Psychologist, Physio Therapist, Occupational Therapist, Speech/Language Therapist, Special Educator, Emergency First Aid, and ENT covered twelve subjects. The program was organized by DSSHA and supported by Kathmandu Metropolitan City (KMC), in Frontline Hospital, Baneshwor. Inaugurated by the Chief of the Social Development Department KMC Mrs. Bimala Koirala. The program's highlight was Mr Ashish Joshi, Self-Advocate who gave the opening remarks. Also, Self-Advocate Miss Grisma Pant who attended the training as a participant,



The training was very fruitful and parents asked for such program's on a regular basis. A pre and post-test questionnaire was given to participants to assess the level of understanding and knowledge gained. Parents filled out feedback forms on further improvements in future pieces of training.



On 10 August 2024 Interaction and consultation Topic "Legal Guardianship and Financial Planning for Parents with Down Syndrome, ID & DD" Advocate Dharma Raj Poudal, Executive member of the High Court Bar Association, Patan was the speaker. The presentation was followed by a Q&A session for parents and siblings and queries were answered in a simple understandable manner. Participants were full of admiration for the speaker and the Program in itself. Demand for the continuation of such events was unanimous.

PAKISTAN

Pakistan Down Syndrome Association (PDSA) Receives Official Registration under Sindh Persons with Disabilities Protection Authority

BY: Abid Lashari

KARACHI: The Pakistan Down Syndrome Association (PDSA) is proud to announce official registration under the Sindh Persons with Disabilities Protection Authority. This significant milestone marks a new chapter in PDSA's ongoing efforts to support and advocate for individuals with Down syndrome in Pakistan.



its

The registration certificate was formally presented by Mr. G. Mohiuddin Asim Siddiqui, Additional Secretary of the Department of Empowerment of Persons with Disabilities (DEPD). The ceremony took place in Karachi, with Mr. Abid Lashari, CEO of PDSA, accepted the certificate on behalf of the organization.

The Sindh Persons with Disabilities Protection Authority plays a crucial role in protecting and promoting the rights of persons with disabilities in the region. Government of Sindh, is running 02 Rehabilitation Centers for children with intellectual disabilities especially children with Down Syndrome in Gulistan e Johar and Gulshan e Hadid Karachi. The Rehabilitation Centers provide free rehabilitation Centers like Physiotherapy, Psychotherapy, Speech Therapy & Occupational Therapy to 200 children in the vicinity.

The Regional Director Regional Directorate of Special Education & Rehabilitation Centres, DEPD Department Karachi visits PDSA Pakistan

Mr. Farman Ali Tanwari Regional Director & Mr. Imtiaz Ahmed Khan, Deputy Director of the Regional Directorate of Special Education & Rehabilitation Centers, under the Department of Empowerment and Persons with Disabilities (DEPD) Government of Sindh, Karachi, recently conducted a visit to PDSA Pakistan. The primary objective of the visit was to assess the organization's requirements for additional financial support and to explore the feasibility of establishing a new unit in Gulshan-e-Hadid, Karachi.

The visit concluded with a mutual commitment to continue discussions and explore potential avenues for collaboration between the Regional Directorate of Special Education & Rehabilitation

Centers, Karachi, and PDSA Pakistan. Both parties expressed optimism regarding the prospect of forging meaningful partnerships in the near future.



Officials from the Sindh Persons with Disabilities Protection Authority (SPDPA) Department of Empowerment and Persons with Disabilities (DEPD) recently conducted a visit to the PDSA Rehabilitation Center located in Gulistan-e-Johar, Karachi an initiative of Pakistan Down Syndrome Association (PDSA) under collaboration of Department of Empowerment of Persons with Disabilities (DEPD) Government of Sindh.



PHILIPPINES

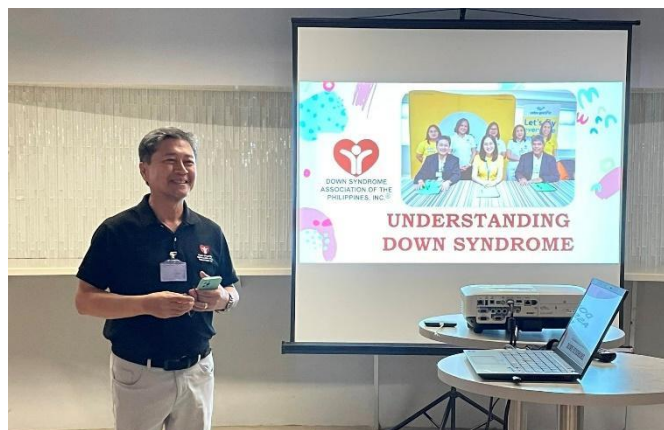
Cebu Pacific partners with DSAPI for inclusive air travel



Cebu Pacific and Down Syndrome Association of the Philippines, Inc. officials sign an MOA as a commitment to inclusive air travel. *[From left to right: Elmer F. Lapeña, DSAPI Chairman; Candice A. Iyog, CEB Chief Marketing and Customer Experience Officer; Luis M. Harder, DSAPI President].*

In an effort to raise awareness and provide support for individuals with Down Syndrome, Cebu Pacific (CEB) has partnered with the Down Syndrome Association of the Philippines, Inc. (DSAPI). A memorandum of arrangement was signed by CEB and DSAPI to initiate joint projects, such as public awareness campaigns, sensitivity training for CEB staff, and travel familiarization exercises for DSAPI members. These programs aim to empower people with Down Syndrome and advance an accepting culture in aviation. "At Cebu Pacific, inclusivity is very much aligned with our purpose. We're dedicated to flying every Juan through our affordable fares and extensive network. We look forward to partnering with DSAPI to enhance our programs and provide an accessible and welcoming travel experience for all passengers. We also hope that the immersion programs will also help members of the DSAPI community," CEB Marketing Chief and Customer Experience Officer Candice Iyog said.

DSAPI, a non-profit organization advocating for the rights and welfare of those with Down Syndrome, welcomes the partnership as a milestone in advancing their cause. "Traveling by air is challenging for most people with Down Syndrome and their families due to a lack of awareness and support systems. We are grateful for partners like Cebu Pacific who share our vision of building an inclusive society where people with Down Syndrome can actively participate and achieve their full potential," DSAPI Chairman Elmer Lapeña said.



With operations in 35 domestic and 24 international locations around Asia, Australia, and the Middle East, CEB is unwavering in its resolve to promote inclusivity and provide more people with access to the gift of air travel.

Source: Daily Tribune, 30 March 2024 | Anthony Ching

Canon Marketing Philippines and Down Syndrome Association celebrate creativity and connection in 3,2,1 Smile Photo Walk



(MANILA, PHILIPPINES), 27 July 2024 – Canon Marketing Philippines, Inc. recently held the "3,2,1 Smile!" photo walk CSR event in collaboration with the Down Syndrome Association of the Philippines, Inc. (DSAPI) at the Dessert Museum in Pasay. This event brought together employees and children from DSAPI for a day of bonding, creativity, and community.



During the event, Canon employees and DSAPI children explored the museum's colorful, dessert-themed rooms, capturing the fun and excitement with Canon cameras. Participants embarked on a delightful journey through each room, bursting with color and whimsical decorations, providing a playful and visually stunning backdrop for the photo walk.

Following the photo walk, the children showcased their talents in a heartwarming performance that highlighted their unique abilities and joy. The day concluded with a shared meal, creating an opportunity for deeper connections and reflections on the experience.



Anuj Aggarwal, President and CEO of Canon Marketing Philippines, Inc., reflected on the event: "At Canon, we believe in the power of imagery to connect and inspire. '3,2,1 Smile!' provided a platform for our team and the wonderful children from DSAPI to share moments of joy and creativity. Our commitment to community engagement is strengthened by such enriching experiences."

Elmer Lapeña, Chairman of DSAPI, echoed these sentiments: "Our ongoing partnership with Canon has brought immense joy and valuable experiences to our children. Events like '3,2,1 Smile!' allow our children to express themselves and form meaningful connections. We deeply appreciate Canon's unwavering support and dedication."





This event marks another milestone in the continuing collaboration between Canon and DSAPI. Earlier this year, Canon participated in the Happy Walk, an event celebrating individuals with Down Syndrome, reinforcing their commitment to supporting the community.

"3,2,1 Smile!" exemplifies Canon Marketing Philippines, Inc.'s dedication to fostering inclusivity and creativity through meaningful partnerships. The company looks forward to more inspiring initiatives that make a positive impact on the community.





Source: Canon Marketing (Philippines) Inc. Website | Latest News & Press Releases July 2024.

SRI LANKA

How Do We Boost The Confidence Level Of Children With Down Syndrome

A STORY IN BRIEF.

Miss. H.N.M. Gaurawi Padiwela is a teenage girl with Down syndrome, now a professional Dancer. Her mother is a teacher in a government school. Mother had noticed the girl's ability to dance from childhood. Both parents had devoted their time by taking her to a traditional dancing school. It's not easy to be a Sri Lankan traditional dancer as there are religious rituals to follow.

The girl was encouraged by parents and given freedom to move with normal children to build up her confidence.

Recently she completed all the religious activities starting early in the morning and had completed all the traditional tests and became a professional dancer.

<https://www.facebook.com/share/p/NcoEZ8N4QgbYy6e8/?mibextid=K35XfP>



Mother Mrs. W. M. Indra Yasawathi, Father Mr. H. N. M. V. Padiwela and daughter Miss. H. N. M. Gaurawi Padiwela girl with Down syndrome.

Departure of a loving daughter with Down syndrome; Based on a true story

Miss. Kumudu Chapa was born in 1998, as the second child of a middle-class family in Kandy. Her father was a government servant and mother was a housewife. Soon after the birth of Chapa, parents were informed that the child was having features of Down syndrome.



She started primary education at the age of 4 years in a special school in Kandy. She was good at music and art work.



Chapa's Art works

When Chapa was 7 years of age, doctors diagnosed a congenital heart disease. One of the major challenges parents faced in her latter part of life was morbid obesity with average weight of 96 kg. Meanwhile, she had a large abdominal hernia and sleeping disturbances. She was on thyroxin for hypothyroidism.

Marked reduction of daily physical activities during the Covid-19 pandemic caused significant weight gain of her. Parents have noticed that she has gradually reduced daily activities during last 6 months of life. It was a challenge for doctors attending surgery for hernia due to obesity, heart disease and poor lung functions. Meanwhile, she was admitted to hospital with a chest infection and passed away due to a non-resolving pneumonia, in spite of optimal medical care.

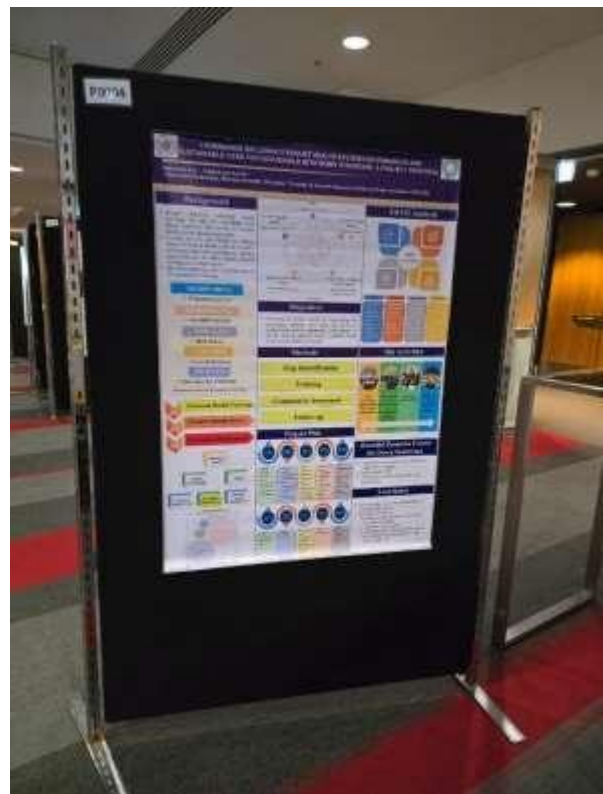
Chapa was deeply attached to the parents and elder brother as well as religious since childhood. It was very difficult for all family members to cope up with her demise. Still, they miss her badly.

One of the main lessons from Chapa's story is that all the individuals with Down syndrome should take possible measures to minimize obesity from the childhood.

(Special thank for the parents giving the permission to publish their experience and photographs)

World Down Syndrome Congress In Brisbane Australia (9th To 12th 2024)

Dr.K.G Dayaratne – Director (JRCFDS), represented the "Jinendhi Resource Centre for Down syndrome, and our country Sri Lanka. Dr. Dayaratne addressed the congress and was at the head table.



TAIWAN



Taiwan Down Syndrome Foundation has marked 2024 as the Year of Sustainability. In alignment with the United Nations' Sustainable Development Goals (SDGs), the foundation has identified four key themes: health, environmental protection, inclusivity, and sustainability. These principles have been integrated into all our services, aiming to ensure the foundation's sustainable growth while providing stable support for people with Down syndrome and other disabilities. We also collaborate with the government, businesses, and the public to build a better society.



To support our sustainability efforts, we have installed solar panels to harness green energy and have established the first green energy sheltered workshop. Our goal is to use 70% green electricity, which is expected to reduce carbon emissions by 7,389.8 kilograms annually.

Additionally, this year, we introduced a "Low-Carbon and Eco-Friendly Gift Box," made from recycled paper and printed with eco-friendly soy ink. The gift box has received FSC™ certification, making it even more environmentally friendly.



In addition, we have begun recycling PET bottles and transforming them into versatile scarves, which are used in gift box packaging. We also use PET bottles to produce World Down Syndrome Day socks. Taiwan Down Syndrome Foundation is dedicated to embedding environmental protection principles throughout its production processes and packaging materials, ensuring that every step we take is in harmony with our planet.

