



March 2024



# Contents

PRESIDENT SPEAK	3
AUSTRALIA	4
BANGLADESH	5
CHINA	8
INDIA	10
JAPAN	13
MYANMAR	15
NEPAL	16
PAKISTAN	18
QATAR	23
TAIWAN	25



#### **PRESIDENT SPEAK**



I am happy to once again present the APDSF e-News—our vibrant platform dedicated to celebrating our remarkable self-advocates and organizations propounding their cause. These pages are a journey of inspiration, empowerment, and advocacy.

Through these articles, we challenge stereotypes and foster a culture of inclusion and acceptance which needs to be shared. Together, we fight for equal opportunities, dismantle barriers and champion the rights of every individual to pursue their dreams.

We are happy to welcome Taiwan as a member of the APDSF. Thanks to them for sending us an impactful article on the wonderful work done by them. Welcome aboard Taiwan.

As we navigate the complexities of life, let us embrace diversity as our greatest strength. Let us celebrate the unique perspectives and talents that each person brings to the table, recognizing that our differences are what make us truly extraordinary.

Together let us build a world where every individual is valued, respected, and empowered to thrive.

# N. Ramachandran

President APDSF



#### **AUSTRALIA**



# **Early bird registration**

Closes 21 March 2024



# Register at www.wdsc2024.org.au

Early bird closes on World Down Syndrome Day!

Australia is busy preparing to host the World Down Syndrome Congress in sunny Brisbane during July this year. The early bird offers a 10% discount on the ticket cost and closes on 21 March 2024, which also marks World Down Syndrome Day.



Patron announcement: Guy Pearce

We are excited to announce internationally acclaimed actor, Guy Pearce, as a patron for World Down Syndrome Congress. Read more about Guy on the Congress website: https://wdsc2024.org.au/patrons.html



#### **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 Centres. In addition to the regular activities the following remarkable activities were performed during the quarter.

# **Celebrating spring season**

Children with Down syndrome and their parents celebrated spring seasons at DSSB Resource Centre at Dhaka. In the seasonal cycle of Bangladesh, Falgun - Chaitra is two months of spring. It is the last season of the year. Spring brings the southerly breeze, milder weather. DSSB family wishes everyone's life to be as colorful and bright as spring.





# **Observing World Valentine's Day**

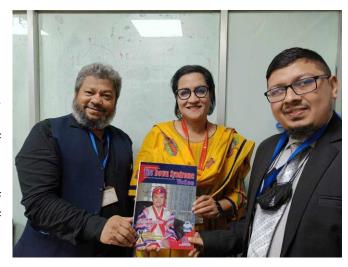
A day long celebration was organized on 14<sup>th</sup> February on the occasion of Valentine's Day. Children and individuals with Down syndrome are the source of our love. On behalf of the Down Syndrome Society of Bangladesh, we wish all the well-wishers of DSSB a very happy Valentine's Day. DSSB Family wishes that everyone's life is filled with love and joy.



# Strengthening cooperation with INGOs, government organization and corporate

# 1. Meeting with Save the Children Fund

A courtesy meeting was held with delegation of Save the Children's Advocacy and Campaign Lead and Down Syndrome Society of Bangladesh. Mr. Sardar A Razzak, Founder Chairman of DSSB informed in detail about the overall activities of Down Syndrome Society of Bangladesh. DSSB hopes to create an opportunity to work together with





Save the Children for the greater welfare of people with Down syndrome in the country.

# 2. Meeting with International Mother Language Institute

A delegation of two members of Down Syndrome Society of Bangladesh participated in a courtesy meeting and exchange of views with the Honorable Director General of the International Mother Language Institute Mr. Professor Dr. Hakim Arif. Director General of International Mother Language Institute confirmed that DSSB Dance Celebrity Team will perform in the opening ceremony of Bhasha Mela 2024 organized by International Mother Language Institute Amai on February 22.



# 3. Meeting with Unilever Bangladesh

The delegation of Down Syndrome Society of Bangladesh met in a courtesy meeting with Shamima Akhtar, Director of Unilever Bangladesh. Unilever Bangladesh Director Shamima Akhtar welcomed the DSSB delegation to her office and assured full cooperation in all DSSB initiatives. Shamima Akhtar, Director, Unilever Bangladesh, was presented with a special memento for her active support in the celebration of Down Syndrome Awareness Month.





#### CHINA

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

- 1. Two-months of parents' self-advocacy successfully completed. Starting with the theme of selfadvocacy 2024: end the stereotypes, the group conducted in-depth discussions, practical exercises and practical situations in life. The central idea of parents' self-advocacy is: I make decisions of my life. The principle is: Balance mental health instead of going to extremes, with awareness, care, aspiration and action.
- 2. A meeting was held to introduce the development history of Up for Down's and some things U.F.D. can benefit to the Down's, including obtaining profits from selling U.F.D.'s products to raise funds for self-advocacy activities in their region. The meeting had a total of 156 participants and 80+ people online at the peak.
- 3. People with Down syndrome in Shenyang have the benefits of medical resources from DPF, U.F.D. is in active contact to promote the cooperation of medical passport project. A professional medical translator from U.F.D. translation volunteer, is invited to participate in the promotion of the **APDSF Medical Passport project**, including the translation of relevant materials and the follow-up of the medical committee work (if the project is established).

Part1: Parents' self-advocacy on Sunday.



Part2: The content shared at the meeting and the meeting attendance.







Part3: Discussion on the medical passport program during the Shenyang trip.





#### **INDIA**

In a world where uniqueness is often undervalued, Down Syndrome Federation of India has proudly championed diversity through its various activities. Our primary goal of empowering self-advocates through various outreach programs and events have enabled our self-advocates to be seen and recognized. Through these events, we shed light on the extraordinary talents and achievements of individuals with Down syndrome. Beyond challenges, we highlight triumphs, fostering a community that celebrates differences and promotes inclusivity.

As we navigate the intricacies of life, let us remember that diversity enriches our collective tapestry.

#### **JANUARY**

## **Purple Fest at Goa**

Purple Fest is India's First-of-its-kind inclusive festival that celebrates persons with diverse abilities. It was at this festival that DSFI decided to conduct its Medical cum therapy camp for Persons with Down syndrome. Our specialists met almost 60 persons with Down syndrome in a day and were able to guide them. Specialists included Endocrinologist, Pediatrician, Orthopedic, Mental Health specialist, Vision specialist, ENT, Dentist and Geneticist

The next day, a Panel discussion was held where parents were able to understand the various issues faced by the self-advocate and how to help them overcome these issues.





#### **FEBRUARY**

# Abhivyakti at Hyderabad

An event to Celebrate diversity was held at Hyderabad where self-advocates had stalls, showcased their talent in all fields of art including performing arts.





# **Medical and Therapy Camp at Rourkela**

The team at Rourkela in association with Home and Hope Special School, Rourkela, SAIL, Rourkela and Team DSFI, Chennai came together to spread awareness, interact with parents and stakeholders to create a collective commitment towards providing an unrestricted environment for persons with Trisomy 21.

Team DSFI comprising of Dr. Surekha Ramachandran, Counsellor and Guide, Dr. Prithie Rekhi, Vision Specialist, Dr. R. Sankar, Orthopedic, Dr. N. Rangarajan, Psychiatrist, Mrs. Hemamalini V S, Special Educator and Dr. Sharanya Krishnan, Speech Therapist came together to assess the self-advocates. After the workshop, an individualized family counseling and assessment session was conducted by the team who then suggested appropriate intervention programs to facilitate the family and person with Trisomy 21. Emphasis was laid on sport and physical fitness as a part of therapy.

The camp ended successfully with all the stakeholders willing to put in the efforts to encourage and provide equal platform to ensure good health facilities and financial assistance for health care.









# **Purple Fest in Delhi**

On 26th February 2024, there were a lot of fantastic events at the Purple Fest held at the Amrit Garden of Rashtrapati Bhavan, where our self-advocates with Down syndrome also performed to a thunderous applause. They showcased their talent in arts and crafts to an appreciative crowd.



Our aim is to create a world where everyone, regardless of ability, is recognized for their inherent value and contributions. Join us in our mission to advocate, educate, and inspire—a journey of love, acceptance, and endless possibilities.



#### **JAPAN**

**Looking back on JDS (Japan Down Syndrome Society) activities in 2023** (mainly related to academic conferences).

This is the year that the Japan Down Syndrome Conference is held once every two years. And JDS also participated in many other academic conferences and events held by related organizations.

In March we decided to cooperate in disseminating the Japanese version of the "Guidelines for Diagnosis and Treatment of Down Syndrome in Adulthood" published by the JDS at academic conferences. In April, The Ministry of Health, Labour and Welfare subsidizes the "Information Site on Testing During Pregnancy" is released. JDS Cooperation's "Life of Children with Down Syndrome" video was released on the site. In October, the directors of JDS participated in the "Emergency Request Meeting for Budget Measures and Revision of Remuneration for Welfare Services for Persons with Disabilities in FY Reiwa 6" (Main Conference Room of the First Assembly Building, House of Representatives) in light of the rapid rise in prices and wage increases.

In Nov.and Dec. the 4th Japan Down Syndrome Conference The 5th Down Syndrome Society academic Meeting "Let's go out on the street" (Osaka)

In the meeting, the Minister Hanako Jimi, of Minister of State for Regional Revitalization, Minister for the World Expo 2025 had her lecture to talk about the future of the Down Syndrome holders and answered some questions.

(The Minister Jimi and the rep. of JDS Mr. Tamai after the conference)

World Down Syndrome Day 2024



The Down Syndrome Awareness Poster 2024, which JDS produces every year, will be photographed by Mr. Taishi Kawada, photographer with Down syndrome (a photo below). We received a lot of applications for poster models. The selected models will be introduced and posters will be unveiled at the World Down Syndrome Day kick-off event. The Down Syndrome Awareness Poster is a poster to let more people know about down syndrome. It will be posted in schools, public facilities, companies, shops, and other places that are visible to many people.

(Mr. Taishi Kawada)

Born in 1982 in Nagoya, Aichi Prefecture, he is currently 41 years old. In 1992, he moved to the United States and participated in the YMCA Summer in Hawaii. Around this time, he began to photograph Hawaiian sunsets. Since 1995, he has been active as a photographer, applying for exhibitions of his works and holding solo exhibitions. In 1996, he won a special prize at the Working





Disability Photo Contest for "Good Luck."

# **Special Web Site Created by JDS**

世界ダウン症の日 公式特設サイト





On March 21, various events are held in various places before and after World Down Syndrome Day, which is designated by the United Nations.

## **Kick-off Event**

World Down Syndrome Day Kick-off Event 2024 Overview February 12, Ushigome Chest Ward Civic Hall

There will be comedy, performances, and talk shows!

Eq. Mr. Saikabe, NHK enterprize producer, making the films: His major works include "I didn't love him because he was my family, but it was my family who loved me," as well as "Deaf Voice: A Sign Language Interpreter in Courtroom," which starred nearly 20 deaf and hard-of-hearing actors, and "The Woman Who Wants to Make and the Woman Who Wants to Eat," which depicts a romance between women.

Mr. Yuka Murakami, poet and Rakugo (traditional Japanese comic storytelling) And more.



#### **MYANMAR**

# MDSA's Steps for a More Inclusive Society



The Myanmar Down Syndrome Association (MDSA) is dedicated to supporting families with members who have Down syndrome. Recently, MDSA has undertaken two significant initiatives – the Gender-Based Violence Workshop and Campaign, and the Vocational Training Program.

The Gender-Based Violence Workshop and Campaign address the crucial issue of gender-based violence. Using

engaging activities and role-playing, MDSA educates people about the importance of treating everyone with respect and standing up against violence. This campaign not only raises awareness within workshops but also extends its impact into communities.

On the other hand, the Vocational Training Program focuses on equipping individuals with Down syndrome with skills that empower them to find employment and enhance their independence. By recognizing and nurturing their unique abilities, this program makes a positive impact on their lives.





Both initiatives underscore MDSA's unwavering commitment to improving the lives of people with Down syndrome and fostering a society that is more understanding and supportive. These efforts reflect MDSA's dedication to creating an inclusive and compassionate community for all.



### **NEPAL**

#### 4 Jan 2024

A girl with Down syndrome 14 years Yojana Aryal trekked up to Pathibhara temple BRAVO. No trekking training ever she did it due to the encouragement and the strong belief of her parents in her that she was capable.

### 19 Jan 2024

"ORIENTATION TRAINING on " Medical Genomics & Clinical Information " joint venture Nepal Health Research Council (NHRC) & MEDICAL GENETIC UNIT, Nepal Academy of Medical Sciences (NAMS) Bir Hospital, Nepal's 1<sup>st</sup> Government hospital Delivering predictive, precise, participatory, preventive, and personalized health, abbreviated as p-Health, is the primary goal of future healthcare systems that can significantly improve care quality while reducing cost.

## 26 Jan 2024

January is **Cervical Cancer Awareness** month

Let us all join hands and prevent our women from losing life by PREVENTION, EARLY DETECTION, AND TREATMENT. CME with a MOTTO "Cervical cancer is curable let no women die of it".

#### 30 Jan 2023

Preliminary meeting to start <u>MULTIDISCIPLINARY CLINIC</u> for people with Down syndrome at Ishan Women & Children Hospital first private Children's hospital.

Medical Director Dr R P Chaudhari (Pediatric Surgeon) Dr Minu Chaudhari (Ophthalmologist) Dr Lalita Joshi (Gynecologist) Founder & President DSSHA -Nepal, Occupational Therapist Ms Shailja Sharma

Together we can change the World. Change, growth, success, accomplishments... These things don't usually happen in one big bang. Little steps get us there.

#### 10 Feb 2024

Rashik Khatri 7yrs child with **Down syndrome** confident future CHEF in the making A wise mother who is making efforts to identify his interest.

Home visit for Focus group discussion (FGD)to assess parents' needs and find the way forward collaborating with like-minded groups and organizations.

#### 14 Feb 2024

SARASWATI PUJA day to worship Goddess Symbol of knowledge and music On this auspicious occasion, the BARDAN ARMY SPECIAL DAY SCHOOL in inaugurated by the Chief of Army Staff General Prabhu Ram Sharma. The school is a joint venture of the Army Wives Association and The Nepalese Army. This 2 storied building is disability friendly with a ramp, Medical Emergency Room, PHYSIO, OCCUPATIONAL, and SPEECH LANGUAGE therapies, and all other amenities needed for a complete school atmosphere. 2 salient points of this school are



- \* proximity to the main tertiary care hospital Shree Birendra Hospital, Chaunni
- \* secure as it is inside the premises of the Army Barrack

I feel proud of my effort as a member of the team working from planning to execution from the inception of this idea to a REALITY today.



#### **PAKISTAN**

Activities of January 2024

# **Executive Summary:**

Pakistan Down Syndrome Association (PDSA) is committed to provide quality services to our children with intellectual disabilities (Down Syndrome, Autism, ADHD, CP & others) through various programs aimed at improving their cognitive, social, emotional, and physical development. We are proud to report that our efforts have resulted in significant progress for

<b>Therapies</b>	<u>Total</u>	<b>Psychotherap</b>	<b>Physiotherapy</b>	<u>Speech</u>	<b>Occupational</b>	<u>Remedia</u>	<u>New</u>
		¥		<b>Therapy</b>	<u>Therapy</u>	<u>I</u>	enrollments in
							January 24
			25				
			25	58	54		
Registratio	67			50	<b>34</b>		20
ns		62				48	20
							Autism:16
							Speech delay:2
							Cerebral palsy:2

many of our children, which has been achieved through a combination of individualized therapy sessions, group activities, and parental involvement. This report provides a detailed overview of our activities and achievements for the month of January.

## **Program Activities:**

**Speech Therapy**: Our speech therapy program continued to focus on improving communication skills for our children with autism and other speech disorders through individualized therapy sessions. Our speech therapist utilized a variety of techniques to help our children develop their language skills.











**Occupational Therapy:** Our occupational therapy program aimed to improve a child's fine motor skills, hand-eye coordination, sensory processing, and self-help skills through individualized therapy sessions. Our occupational therapist utilized a variety of techniques, including sensory integration therapy, hand therapy exercises, and adaptive equipment training, to help our children develop their motor skills.

















# **Physical Therapy:**

Our physical therapy program aimed to improve our children's gross motor skills, balance, coordination, strength, flexibility, and endurance through individualized therapy sessions as well group activities such gymnastics classes for children with autism spectrum disorder (ASD and with physical disabilities. Our physical therapist utilized a variety of techniques such as functional movement exercises and assistive devices to help our clients develop their physical abilities.

















## **Behavior therapy:**

Behavior therapy for special needs involves using various techniques to address challenging behaviors and teach new skills. It's all about creating a positive and supportive environment to help individuals learn and grow. Therapists often use techniques such as positive reinforcement, visual aids, and structured routines to help individuals with special needs. The goal is to improve their quality of life and help them thrive in their daily activities.











# **Informal education:**

Non-formal education for special needs focuses on addressing specific learning challenges and helping individuals catch up in areas where they may be struggling. It often involves personalized learning plans, targeted interventions, and extra support to help individuals build essential skills. The goal is to empower them to succeed and reach their full potential.









#### **QATAR**

# The role of the QISH Center towards Down Syndrome.

We are the Qatar institute for Speech and Hearing in Doha - Qatar. It is considered the first center for people with special needs licensed by the Qatari Ministry of Public Health for 13 years. We serve all people with special needs in Qatar.

Regarding our services provided to people with Down Syndrome, thanks to God, we provide them with all services, starting with speech and language sessions, psychological sessions, occupational therapy, physical therapy, and assistance in developing their scholastic and academic performance at school, as well as audiological services.

Praise be to God, we have a good number of people who help children enroll in schools and help and train them to pass the necessary assessments at school.

As for our social duty, we always organize events and entertainment activities for children with Down syndrome, in addition to training workshops for parents.

Indeed, we are a special, simple part within the ancient Qatari society. We always receive support from the government and people of our beloved country, Qatar, in the event that we request any special request from this distinguished group within our society.

The government here provides us with entertainment, for example, but not limited to, which is always free, in addition to health and education services.

Shedding more light on our children with Down Syndrome is our current role, which we are carrying out in a more effective and positive manner, and it was pledged by the Group Chairman, Mr.Eissa Al-Mannai, and the Group Founder Mr.Niyas Kavungal, who instructed us to communicate with the Asia Pacific Down Syndrome Federation and provide available means for participation. With them in the awareness activities available in our country Qatar.

Last but not least, Down syndrome is a beautiful responsibility. We are proud of the initiative to increase the spotlight on them in Qatari society.











#### **TAIWAN**

# **Down Syndrome Foundation R.O.C (Taiwan)**

To provide high-quality and dignified long-term care services for severely disabled individuals, the Taiwan Down Syndrome Foundation has established the first 24-hour comprehensive institution with Smart Al facilities in social welfare.

The facility is designed with a "home" in mind, consisting of ten small households. The use of bright and warm colour tones creates a professional, safe, and friendly environment, providing residents with the opportunity to experience quality care that may delay ageing and extend healthy life. This facility is also the first in the country to integrate Smart AI into daily services for individuals with disabilities. This includes a safety monitoring platform, sleep monitoring, bedsore prevention, spinal protection, and intelligent mattresses that relax muscles. "Sensor devices" can detect abnormal conditions such as breathing, leaving the bed, falling, and prolonged immobility. These devices will immediately alert caregivers and provide necessary assistance on time.

Several pieces of furniture in the facility are specifically designed to assist those who need it. For example, one of the ergonomic aids is used to automatically adjust the height of bathroom sinks based on the height differences of those being cared for. This makes tasks like tooth brushing and face washing safer. By enabling people with disabilities to perform tasks independently, this approach fosters rehabilitation and provides practice opportunities.

The origin of technology always originates from human nature. Technology is created from humanity's warmth and thoughtful consideration, and it is designed not only for people with disabilities but also for caregivers. The no-lift Policy avoids the risk of occupational injuries, making caregiving easier and less burdensome for caregivers while at the same time improving the quality of care. This creates a friendly and healthy working environment for caregivers. Our efforts are contributing to a change in the care model for future disabled individuals in Taiwan.







