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Hello everyone:

Another eventful year for the APDSF is speeding by. With events like the World Down Syndrome Day in March, October Awareness month and the AGM that was different from the previous years, it has been a memorable 2023.

Our AGM held in October was an eye-opener for us. We realized how important it is for us as a group to share our knowledge with one another. The Train the Trainer sessions of therapists from India and Singapore was highly appreciated. The practical session made a difference to the local therapists who now armed with knowledge are eager to pass on their learning.

Another interesting session that was organized was that for the Mountaineering Workshop for self-advocates by Col. Thapa of Nepal. His presentation was well received, since it gave new fitness goals for our self-advocates. Who would have thought that our self-advocates would one day be able to reach the Everest Base Camp. That is what the goal now is.

Our medical committee led by Dr. Bhavani Sriram has now created a team of medical experts across the APDSF region. This team is now gearing up to start using the Medical passport by modifying it according to the sensibility of their region. The guidelines for neo-natal counselling are also expected to be rolled out shortly.

We hope to collaborate with other like-minded bodies in order to spread more information about Down syndrome. Inspite of being the most common genetic condition, it is still not well-understood. We are looking at reaching out to many more organizations in the disability space that are yet to understand Down syndrome. Our aim is to assist them in spreading awareness and providing information that we have at our disposal. This is our contribution in making the region a Down syndrome friendly place.

In this festive month,

“Seasons Greetings and all the very best to each and everyone of you for a wonderful year ahead.”

Regards,

N. Ramachandran
President - APDSF
DSAN recognised with international award

Down Syndrome Australia has been named the winner of the Inclusive Organization award. This is an international award run through Down Syndrome International that recognizes outstanding work in 5 fields across the globe.

DSA was selected because of the work of the Down Syndrome Advisory Network (DSAN) - a group of people with Down syndrome that advises Down Syndrome Australia. DSAN has been working as a leadership team with Down Syndrome Australia for six years. The group meets monthly and helps advise on all of Down Syndrome Australia’s project work. They also teach people with Down syndrome about their rights and how to speak in public.

DSA helps launch Australian first: National Centre of Excellence in Intellectual Disability Health

DSA is excited to announce the official launch of the National Centre of Excellence in Intellectual Disability Health.

This Centre will be a game changer - the first of its kind in Australia to bring together strong advocacy, clinical and research experience in intellectual disability health.

Down Syndrome Australia has been working as a founding partner with consortium members to establish the Centre. The Centre will be a catalyst for action to ensure people with intellectual disability have improved access to quality, timely and comprehensive health care.

DSA's Health Ambassador, Naomi Lake, spoke alongside Federal Assistant Minister for Health and Aged Care, The Hon Ged Kearney, as part of the Centre launch.

DSA Chair, Dr Rebecca Kelly also spoke at the launch, remarking that the Centre is a "real hope for change." The Centre is supported by the Federal Government who have committed $23.9 million over 4 years, with a commitment to ongoing funding.
World Down Syndrome Congress

Registration and call for presentation abstracts are now open! One of the best parts of Congress is connecting with the Down syndrome community to learn new information, exchange ideas and make life-long friends. That’s why Congress welcomes you to submit an abstract for a presentation you would like to give. The sky is the limit: artwork, talks, workshops – you name it, we want to hear about it!

There are many options you can choose from, including:

- Oral Presentation
- Poster Presentation
- Workshop Presentation
- Artistic Performance
- Artistic Display
- Health and Professions and Research Day Meeting

To find out more about the Congress, go to [www.wdsc2024.org.au](http://www.wdsc2024.org.au)

To make sure you stay up to date with the Congress, register your interest here: [Expression of Interest - Contact Details (eventsair.com)](http://eventsair.com)
Recently, we have four important things to share with our APDSF members:

1. October is Down syndrome publicity month. On October 28th, Ma Wanqiu, the core member of Up for Down’s China, held a country concert for the DS children in Liangzhu Warm Village, Hangzhou. A total of 35 programs were prepared, and about 70 people participated, including 20 performance volunteers, 5 work volunteers and 12 DS families from all over the country.

2. A six-month English learning group, initiated by 15-year-old Tang Yifeng, has provided English learning opportunities for parents who want to attend international Down Syndrome conferences. At present, with Yifeng’s mother Zhang Lei taking over his responsibilities, the group has completed one month of study, and is going on the second stage.

3. Up for Down’s China held two team building activities, one in Shanghai on October 14th and the other in Hangzhou on October 21st. We have established the purpose to work hard for Down Syndrome group regardless of reward. All members start with self-advocacy, practice loving themselves.

4. A three-month parent self-advocacy campaign has been launched and four sessions have been held so far. We have established the principles of regulating internal balance instead of going to extremes, with awareness and care, aspiration and action.

Part1: U.F.D. Hangzhou Liangzhu Warm Village country concert On October 28th
Part2: One month after learning English, Cheng Jieping from Kunshan shared her notes in the study group.

Part3: U.F.D. Shanghai team building group photo On October 14th

U.F.D. Hangzhou team building group photo On October 21th

Part4: Parents’ self-advocacy on Sunday and Down Syndrome’s self-advocacy on Saturday
India is buzzing with activities this year and DSFI is proud to be a part of the changes that we are witnessing in the attitude of people and in the awareness that is being created through various activities in the country.

IIDSC 2023

DSFI organized the 7th Edition of our annual conference – the India International Down Syndrome Conference at Jaipur, Rajasthan from 14-17 September 2023. As usual, there was knowledge sharing in the form of panel discussions – with both doctors and therapists for the various issues faced by our self-advocates. A lot of unanswered questions thus far found answers and parents as well as other attending doctors and therapists gained a lot of different insights.

The session was preceded by a talk on health by our self-advocate, Ms. Devanshi Joshi.

The doctors were specialists in the field of – Vision, Neo-natal and Pediatrics, Endocrinology, Genetics, Orthopedics, ENT, Mental Health and Dental Care.
The Doctors’ panel discussion was followed by a similar discussion by therapists in their area of expertise. These included – Physiotherapist, Special Educator, Speech Therapist and an Expert on ADL. A self-advocate, Mr. Sharan Delhivala spoke about his journey to Health and Fitness prior to the session.

These sessions were followed by some interactive sessions for siblings where these siblings bared their hearts out with regard to their sibling with Down syndrome. It was an emotional session with not a single dry-eye in the audience.

There were practical sessions too where parents were practically taught how to teach their self-advocates and provide them with therapy. These sessions were the first of its kind and widely appreciated since the biggest problem that parents usually face is to communicate with them.

There were games and cultural performances by our self-advocates that made the event a wholesome one.

**October - Down Syndrome Awareness Month Celebrations**

The whole of October saw DSFI highly active on the social media with some activity or the other on a daily basis. Our self-advocates performed and showcased their talent that was then shared across platforms.
There were many voices that spoke in unison about inclusion, including the Resident Coordinator for the United Nations in India, Mr. Shombi Sharp and the Secretary, Ministry of Disability Affairs, Mr. Rajesh Aggarwal.

The President of India, Ms. Droupadi Murmu also felicitated one of our Self-advocates and was presented with a bag made by him, which she highly appreciated.

**Creating a Change in Nepal**

Our therapists and counsellors in association with Singapore did a camp at Kathmandu, Nepal during the APDSF AGM to train the therapists there on issues related to children and adults with Down syndrome. They were trained on how to provide therapy to Persons with Down syndrome. It was highly appreciated and a follow-up session is also being planned.
Over 400 professionals and people with down syndrome gathered at the 4th Meeting of Japan Down Syndrome and 5th Academic Meeting of Japan Down Syndrome

The 4th Meeting of Japan Down Syndrome and 5th Academic Meeting of Japan Down Syndrome were held in Osaka on 11th -12th November. By bringing together and networking with diverse people, including those involved, researchers, medical professionals, supporters, and family members, we create a society where people with Down syndrome can lead happy and stable lives. The key phrase of this year was “Let´s go to town -solidarity with people and society.” Over 400 professionals and people with Down syndrome gathered at the meeting. https://www.supportoffice.jp/jds2a/
MYANMAR

Myanmar Down Syndrome Association’s Endeavors for Inclusion

Over the past few years, the Myanmar Down Syndrome Association (MDSA) has faced challenges posed by political instability, crises, and the ongoing global pandemic. Despite these obstacles, the organization remains unwavering in its commitment to fostering inclusivity for Persons with Disabilities (PWDs). Guided by the spirit of "Never Say Die," APDSF has actively sought ways to shape the journey of social acceptance for PWDs within the community.

By using virtual techniques and the advocacy ways in practical fields, we were able to continue the community awareness raising activities within 2 years. After that, we continuously implemented the capacity building training and programs for people with Down syndrome(PWDS). As the result, we could see the development of PWDS and they improved a lot not only in their individual life but also in their community. Therefore, we move forward our next step to promote the inclusion culture among the PWDS and other normal developed children. We arranged an awareness workshop which is about inclusion and disabilities to the parents, volunteers and other school teachers to build the bridge among them. Next, we organized the Personal, Social, Health and Education (PSHE) Training for mainstream school children and PWDS which became the most successful one because of the result of the training.

We could build the trust and understandable relationship among PWDS and mainstream school children.

For the future activities, we are planning to reach the steps of creating job opportunities especially for PWDS from Myanmar community.

Although the journey is difficult, we will continue to reach the goal which is building the inclusion space for PWDS not only locally but also internationally. We do believe that we can initiate the inclusion culture in the community by arranging such kinds of activities, however we do need the funding support and community support from every sector. So, let’s hand in hand for creating the beautiful lives of PWDs in the world'.
Advantages and Disadvantages of Social Media and Youth with Disabilities Webinar

Down Syndrome Family Myanmar and New Heaven Learning Center (Taungyi) held an online webinar as a commemoration of October Down Syndrome Awareness month.

On the 15th of October 2023, a webinar was held on the topic of advantages and disadvantages of social media for youth with disabilities. The webinar took place from 2:00 to 4:00 pm and was conducted through the online Zoom application. Over 25 participants, including parents, teachers, caregivers, and individuals from Taungyi in the Shan State, joined the session.

The purpose of this webinar was to raise awareness among the audience about the importance of protecting oneself while using social media and how to utilize it positively. Additionally, the webinar aimed to provide a platform for individuals to share their experiences and find solutions to the issue of social media addiction.

Social media has become an integral part of our lives, offering numerous advantages for individuals with disabilities. One of the key benefits is the ability to connect with others and form a supportive community. Social media platforms allow individuals to share their experiences, challenges, and successes, creating a sense of belonging and understanding. This is particularly crucial for youth with disabilities who may feel isolated or misunderstood in their daily lives.

Another advantage of social media is the opportunity for self-expression and creativity. Many individuals with disabilities have unique talents and perspectives that can be shared through social media platforms. This allows them to gain recognition, build confidence, and even explore potential career opportunities.

Furthermore, social media can be a powerful tool for advocacy and raising awareness about disability rights and inclusion. By sharing their stories and experiences, individuals can educate others and promote positive change in society. Social media campaigns have played a significant role in challenging stereotypes and promoting a more inclusive society.

However, it is essential to acknowledge the potential disadvantages and risks associated with social media use. One of the main concerns is the potential for addiction. Spending excessive amounts of time on social media can negatively impact mental health and overall well-being. It is crucial for individuals, especially youth with disabilities, to learn how to use social media responsibly and balance their online and offline activities.

Additionally, there are privacy and security risks associated with social media use. It is essential for individuals to be aware of the potential dangers and take necessary precautions to protect their personal information. The webinar aimed to educate participants on privacy settings, online safety measures, and the importance of being cautious while interacting with strangers online.
Overall, the webinar on the advantages and disadvantages of social media for youth with disabilities provided valuable insights and knowledge to the participants. By raising awareness about responsible social media use, the webinar aimed to empower individuals to navigate the online world effectively. Moreover, the platform allowed participants to share their challenges and find solutions to issues such as social media addiction.

In conclusion, social media can offer numerous advantages for youth with disabilities, including the ability to connect with others, express themselves creatively, and advocate for disability rights. However, it is crucial to be aware of the potential risks and disadvantages associated with social media use. The webinar held on the 15th of October 2023 aimed to provide participants with the necessary knowledge and tools to protect themselves and utilize social media positively. By sharing experiences and finding solutions together, the webinar fostered a sense of community and empowerment among the participants from Taungyi.
APDSF, AGM 2023 hosted in Kathmandu, NEPAL at Marriott Hotel from 25th – 27th October with various activities which coincided in the Down Syndrome Awareness month OCTOBER.

The highlights

- The event was inaugurated by the Deputy Mayor of Kathmandu Metropolitan City Ms Sunita Dongol. She spoke on the various aspects faced by the community with Down syndrome and showed her commitment to support for their better future. There was a Cultural dance performance by Self Advocates at the end of Inaugural session the program was covered by Media and Press.
- Host country Nepal welcome dinner by President DSSHA -Nepal & Vice President APDSF (Rtd.Br.Gen)Dr Lalita Joshi at Dwarika, a Heritage Hotel.
- A feather to the cap was the much-needed Therapist Session conducted by Special Educator, Speech language Pathologist, Pediatrician and Adult Empowerment Specialist for educating Therapists, parents and care givers from various organizations and also raise awareness about the specific needs in improving the standards of life of DS population in Nepal. This session was highly appreciated by the participants and said that such events should be encouraged so that there is more awareness about the specific needs of People with Down syndrome to make their life enriched and dignified.
- Sightseeing arranged for the AGM delegates after the conclusion of the event to important places in Kathmandu.

PLANS for coming year 2024 –Promotion of inclusion for our self-advocates with Down syndrome.

- **Study tour** on 29 October 2023 by team from DSA Singapore & DSSHA -Nepal to Council for Technical Education and Vocational training (CTEVT), Sanothimi and interaction and planning of **Pilot project in Housekeeping Training** for adults with DS with placement options discussed with the officials there. Further planning and execution meeting would be continuing till project completion.
- **Early intervention** programs and trainings promotion.
- **Inclusive mainstream schooling** efforts will be strongly continued along with Awareness, orientation in Private and Government schools.
PAKISTAN

EVENT REPORT

DOWN SYNDROME AWARENESS MONTH

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<td>Funded By</td>
<td>CMB International &amp; SIOVS Hyderabad</td>
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<tr>
<td>Organized By</td>
<td>Pakistan Down Syndrome Association (PDSA) Karachi</td>
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<tr>
<td>Date</td>
<td>09th October 2023</td>
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<tr>
<td>Venue</td>
<td>Hotel Marriott, Karachi</td>
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<td>Target Audience</td>
<td>100 Families of Children with Down Syndrome</td>
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Proceeding
In October, Karachi was abuzz with awareness and celebration as the Pakistan Down Syndrome Association (PDSA) partnered with CBM International and SIOVS Hyderabad to mark Down Syndrome Awareness Month. The event took place in the elegant Marriott Hotel Karachi, bringing together advocates, professionals, and families to shed light on Down syndrome.

The occasion was graced by esteemed guest speakers, including self-advocate Down Syndrome children Ms. Syeda Alisha Amin uddin & Ms. Hassan Patel other Dignitaries Mr. Muhammad Omar Soomro (Minister for Law and Human Rights), Mr. Tauha Ahmed Farooqui (Secretary Department of Empowerment of Persons with Disabilities), Mr. Aman Khan (Program Manager, CBM International), Mr. Jalil Ahmed Rajpar (representative, SIOVS), Mr. Iqbal Detho (Chairperson, Sindh Human Rights Commission), Mr. Abid Lashari (CEO, PDSA), Mr. Ghulam Nabui Nizamani Head of Disability Program HANDS, Dr. Iffat Sultana, Mr. Tariq Hussain Channar, Mr. Robin and Ms. Faiza Jawad.

The speakers passionately emphasized that Down syndrome affects individuals across the human spectrum and is the most common chromosomal condition. Every year, approximately 6,000 babies are born with Down syndrome, equating to a 1 in 700 chance. The prevalence of Down syndrome increases with the mother’s age and is associated with physical growth delays, characteristic facial features, and intellectual disabilities. Despite these challenges, the speakers highlighted that individuals with Down syndrome can lead fulfilling lives. Their average IQ is akin to that of an 8-year-old, yet they have the potential for happiness and longevity.

Down Syndrome Awareness Month, celebrated annually in October, serves as a focal point for raising awareness and advocating for the rights and inclusion of people with Down syndrome. While awareness and support are crucial throughout the year, October becomes a time of intensified efforts. The campaign aims to educate people about Down
syndrome, its symptoms, and the significance of the awareness month. Moreover, it serves as an opportunity to celebrate the remarkable accomplishments of individuals with Down syndrome and show support for their families and caregivers.

A significant achievement highlighted during the event was the increase in life expectancy for individuals with Down syndrome. In 1983, their average life expectancy was 25 years, but now it has risen to 60, according to the Global Down Syndrome Foundation. This progress underscores the impact of awareness campaigns and medical advancements on improving the quality of life for those with Down syndrome.

The attendees were encouraged to actively participate in Down Syndrome Awareness Month by learning about Down syndrome, engaging in conversations with friends and family to dispel stereotypes, and sharing information on social media platforms using the hashtag #DownSyndromeAwarenessMonth. Supporting organizations working with people with Down syndrome was also emphasized as a means to contribute to creating a more inclusive and accepting world for individuals with Down syndrome.

Throughout the event, the efforts of the Department of Empowerment of Persons with Disabilities (DEPD) of the Government of Sindh were highly appreciated because this is the Department which deals Disability & first time in the history of Pakistan DEPD declared Down Syndrome as separate category of Disability earlier it was counted in mental retardation. Participants acknowledged the progress made and urged for continued efforts to bridge existing gaps, ensuring a brighter and more inclusive future for individuals with Down syndrome in Pakistan.
Sindhi TV Channel Awaz Report
https://fb.watch/nCsEt2nAxQ/?mibextid=Nif5oz

Daily Pak Bulletin Karachi
https://pakbulletins.com/news-detail/MzY2Mw
PHILIPPINES

DOWN SYNDROME is the most common genetic disorder affecting one in every 800 children in the Philippines. It is estimated that there is one person with Down Syndrome born every 4 hours. Most children with Down Syndrome have mild to moderate cognitive disability. About half of the children who have Down Syndrome are born with a heart defect. They would need close monitoring, intervention and care for thyroid problems, elevated uric acid, respiratory infections, constipation, hearing, visual, speech and dental problems, among other Health concerns throughout their lives. But with proper medical attention and support from Family and the Community, people with Down Syndrome can live as normal lives as possible.

HEALTHCARE FOR DOWN hopes to promote Health Awareness and Education among family members of persons/kids with Down Syndrome, provide “Basic and yet Critical Health Care Intervention and Solutions as well as Continuity of Care for persons/kids with Down Syndrome.

The program also hopes to create Awareness and Continuous Support from Health Industry stakeholders, groups, and individuals who CARE.

This year the Down Syndrome Association of the Philippines, Inc. (DSAPI) had two (2) “Healthcare for Down” (a FREE Clinic for Persons with Down Syndrome) in partnership with PayPal Philippines and Lenovo Philippines. About 150 persons with Down Syndrome were given quality medical services.
Doctors from various fields of specialization (Pediatrics, Family Medicine, Cardiology, Endocrinology, Ophthalmology, ENT, Genetics, Orthopedics, Pulmonology, Dermatology, Neurology, Psychology, and Developmental Medicine), Dentists, Physical, Occupational & Speech therapists, Nurses along with allied Medical fields, concerned Organizations and Individuals have all United to Care for People with Down Syndrome with their Special gifts of Time, Talent and Treasure.
To PayPal Philippines, Lenovo Philippines, the health-care professionals, the non-medical volunteers, and to everyone who supported the cause, THANK YOU and CONGRATULATIONS!!! All efforts in the pursuit of a better, healthier and a more sustainable community for children with Down Syndrome. To God be the Glory.

LUIS M. HARDER

President, Down Syndrome Association of the Philippines, Inc.
Biggest improvement within the world of Down syndrome of Sri Lanka - Last two years

Sri Lanka has credited a comprehensive free education system for all during past nine decades. The main provider of education for children with special needs are special education units attached to schools, special schools under the ministry of education and a limited number of private institutions. Currently, there are eight special schools and 450 special units in the country, catering to children with learning disabilities.

Ministry of education started a well-organized inclusion and integration program with regards to the special education since 2020. According to that, the education assessment committees are to be established for each regional education office. This committee should perform a detail assessment of all the children with special needs by the age of four years and categorize students into the following groups.

1. Minimally affected children - inclusion into the main stream schools from the beginning. There will be a 3% quota for child with special need in school entry of 2024.

2. Strategy class room - Initially supervised in a special unit and direct into main stream classes subsequently

3. Aided special schools

4. “Travel teacher” for severely affected children - new concept to be implemented. Teacher visits the child at home or a convenient public place in regular basis.

Program is not yet fully implemented in the entire country. It will be a massive positive move in the field of education of children with special needs in future.

2024 - Continuation of Activities of JRCFDS - Sri Lanka.

1. New Developments in the organization After almost 30 years’ wealth of experience, we have managed to identify the correct Vision and Mission of the JRCFDS. Accordingly, we are in the process of streamlining the operations of the organization. New website will be available very soon. www.jdownsyndromelanka.org

2. Home for the aged people with Down Syndrome We managed to motivate one of the Homes for the aged to accommodate aged people with Down Syndrome. They have a chain of homes in the island. For the first time two boys with Down Syndrome have joined this home. We assisted the home by donating a Television, a DVD player and a TV stand.

3. Down Syndrome awareness project Dr Dayaratne initiated Down Syndrome awareness presentations to Medical Professionals at all levels in collaboration with the regional medical offices of the respective districts. Already covered two districts. Further, an online awareness
presentation programme was conducted for the medical students of the Rajarata medical college.

4. Professionals to serve - an ongoing project since 1997

5. Listening and Counseling This is an ongoing programme. Parents of children with down syndrome listen to the depressed mothers of newly born children with DS. Two parents are following the DS awareness course of APDSF. These two parents are also joining the existing team. But our professional counsellors are available for service for further management.

6. Assisting the children’s homes or organizations working for people with Down Syndrome. This year financial assistance was given to one home assisting the people with Down Syndrome.

7. The founder Mr. Galgamuwa attended the UN GCAP and UN SDG summit in New York from 17th to 23rdSeptember. Mr. Galgamuwa tabled a proposal to safeguard the interests and rights of people with DS.
8. JINENDHI was a special guest at the “Step up Walk for Children with Down Syndrome” organized by the F.R.I.E.N.D.S Down Syndrome Advocacy Group in Frederick City / Maryland, US. We learned about many great projects and programs they do for the well-being of the People with Down Syndrome. Many fun activities were there to participate.

9. The department of education has taken the following steps to give a better attention to children with special needs: A) Strengthening the existing classes for special need children by providing infrastructure and trained teachers. B) A committee was appointed to do a complete assessment of the children

10. SPECIAL OLYMPICS.

Mr. Galgamuwa has started an initiative to strengthen our relationship with the headquarters in Washington, D.C., United States, and requested to provide an opportunity for JRCFDS to work with them for the benefit of People with Down Syndrome in Sri Lanka.

As a result of this request, Mr. Bradley, Director at the Special Olympics Asia Pacific will be visiting Sri Lanka in December for a discussion. One of our Co- Directors, Air Vice Marshal (Rtd.) Lakshman Ranathunga agreed to coordinate with Mr. Bradley.

11. Establishing Down Syndrome welfare clubs in underprivileged areas is continuing in 2024.
12. Talent shows for the children with special needs

PHF. G.A.W.G. Galgamuwa (Ex Lieutenant VNF)
- Sustainable Development Diplomacy Governor - UN SDG - SUNFO.
- Director General (GEYEF )
- Director - Jinendhi Resource Centre for Down Syndrome.
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