ASIA PACIFIC
DOWN SYNDROME
FEDERATION

**January – March 2021**

# Contents

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DOWN SYNDROME
FEDERATION

# PRESIDENT SPEAK

Hi everyone,

I would like to wish all APDSF members, their families and members of the organization all the very best for this year.

Only some countries have responded to our request for Newsletters and since we need to respect those who took time out to send us information about the activities in their countries, we are pleased to present the Newsletter for the first quarter of 2021.

2020 has not been a good year for all of us. We have had to face hardships, however, we have also emerged stronger. All the initiatives taken by our members have made us feel proud whilst we have been supporting our dear ones.

Our self-advocates have been phenomenal – understanding the concept of wearing masks, social distancing and staying at home.

As the saying goes, “this too shall pass” and surely with the advent of the vaccines, we shall soon be back to our normal routines. Until then, let us all stay together and be passionate about our cause to create an inclusive society for our children.

**N. Ramachandran**
**President – APDSF**

# INDIA

## The Year that was 2020 – Down Syndrome Federation of India Brings to You 2020 at a glance

***DSFI has some fantastic news to start this Newsletter and this year with. Persons with Down syndrome in India have been recommended under the PRIORITY LIST for the Corona Vaccine, which means they would be vaccinated at the earliest. https://www.livemint.com/news/india/india-to-give-priority-to-people-with-down-syndrome-for-covid-19-jabs-11614399839561.html***

2020 will always be remembered as the Year of Corona. This insignificant virus ensured that it will never be forgotten, what with the lockdown and its cataclysmic effect across the universe without any sympathy. Yes, it was a year that spread a lot of negativity, but we at the Federation also saw a lot of positive changes in our lives. Below, we take a look at the Year that was for Down syndrome family.

1. In Jan 2020 DSFI entered Madhya Pradesh with its first ever camp in the state attended by over 100 people. We got the support of the District Administration to ensure the success of this camp.
2. Feb 2020 we went to Raipur to finalize the venue of our IIDSC 2020. The location, the venue and the dates were finalized for the event. The agenda was also drafted
3. March – Down Syndrome Day Celebrations were planned, when the Virus started the war against us. Sponsors had been roped in and the events had been finalized. Various schools had confirmed participation in the event. But due to the ban on gatherings, we had to shelve the plan. AND THE LOCKDOWN BEGAN.
4. April - The beginning of the lockdown saw Rekha Maa start providing her MANTRAS to keep the Down syndrome Family together. Every day was a fun day with some activity of the other to keep the children and the parents occupied. A session on Yoga was one of the highlights of the period.

Rekha Maa's Lockdown Mantra

Mantra - 17

Let's Go for a PICNIC...To the Living Room.

You need not always go out to have FUN. Time to have some FAMILY FUN TIME at home. Enjoy your picnic lunches, play some picnic games, catch up on the old songs, Relax, Talk, Laugh..There is so much you can do at your HOME PICNIC.

Cherish these moments. They will become your memories.

Do it TOGETHER...As a FAMILY

10 April 2020

Rekha Maa's Lockdown Mantra

Mantra - 37

Chuk Chuk Train, play the game...

It's vacation time. Time to take everyone in the FAMILY for a trip and that too in your personal train.

Let the children decide who is the Engine, who is the bogie and any other character they want to be.

Go to their dream destination. And on the way you can of course see the sea, the mountains or the elephant..Leave it to your imagination. Each FAMILY member can play a role and treasure these moments.

01 May 2020

Rekha Maa's Lockdown Mantra

Mantra 10

Get on Board..with exciting games

Today, Bring Out the Child in You

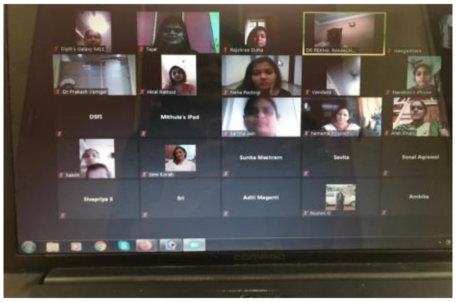
Go back to the Board Games that were so much FUN! Enjoy this with your LOVED ONES Snakes and Ladders, Ludo, Chess, Parchisi...Just get out the old Boards and start Playing...

The KEYWORD is..TOGETHER As a FAMILY...

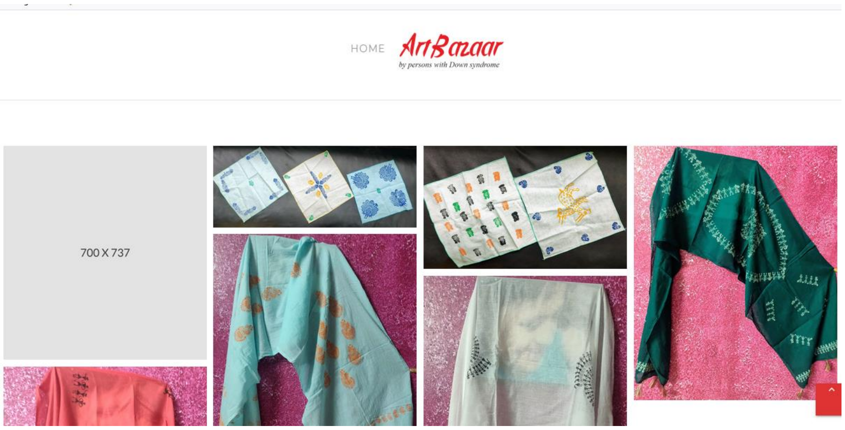
03-April-2020

5. Parents were offered Counselling services and Therapies Free of Cost during this period by the Federation because we understand the Pain of not knowing what to do during these times. Every week there was a session by experts from various fields that was meant to support parents and our dear ones with Down syndrome.
6. May - The month when IIDSC 2020 was planned. We did not want parents to be disappointed. So the event was held Virtually on 1 day – 28th of May 2020 A survey that was conducted by the Federation brought out the happy news that Family bonding was getting stronger during the lockdown. Parents were bonding with their children and Quality time was now a norm amongst families.

7. June was the month of mothers, where the first virtual Mother's meet was organized to boost their morale and help them keep their children engaged. It was also the month when the first online course for Down syndrome was launched



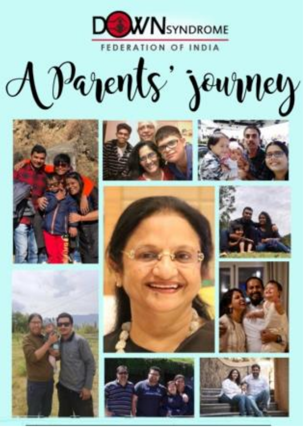

8. July - The idea of an Art Bazaar – an exclusive showcase of the Art and Craft work done by our children was formed. And we started receiving some outstanding work that was posted on the site - [http://art.downsyndrome.in](http://art.downsyndrome.in).



9. August – The First Online Medical Camp for Down syndrome in the World was organized by the Federation in association with the Bangalore Hamsafar group . This was a huge success with Happy parents who never expected this during the lockdown. All the doctors who came for the session volunteered their services which was a wonderful gesture on their behalf.



10. September was the beginning of two interesting sessions – one – a story telling session with Shivani Dhillon who mesmerized children with her lively stories and learning with Fun. Another session was by Ms. Parul Singh, who brough FB Live to life connecting and bonding with the parents with her interviews that brought Hope to all parents.



Every tuesday 4:30-5:30

STORY TELLING

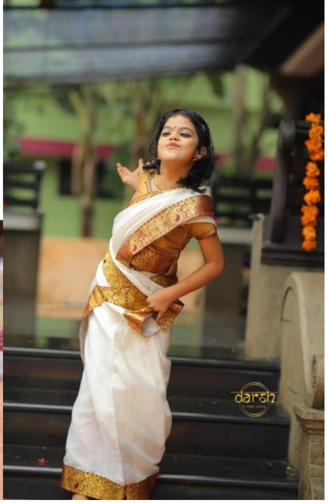
This November we will talk and learn about new things like how to wait patiently, our safety & about Coronavirus through stories, music & dance. There will be lots of interaction and fun with Shivani Aunty.

11. October – the Down syndrome Awareness month was all about Celebrating our Children with Down syndrome. Our Self-advocates were crowned as "Jyothisho Yoddhas – the warriors who lit up the world" – one every day of the month. The next online camp was organized by the Down Syndrome Association of Tamilnadu.

12. November – the month of Children's Day! A caption contest was organized for Parents. They were asked to send in a picture of their child along with a caption that best described their child. Adding another Feather to her cap was our President Dr. Surekha Ramachandran's much appreciated address on Self Advocacy for a global audience. This was organized by the Al Noor Rehabilitation and Welfare Association for People of Determination, Abu Dhabi.

ખાઓ, ખવડાવો અને ખૂશ રહો ! (Eat, feed and be happy!)

I am not defined by my battles,
I am defined by my victories.



What makes me different
is what makes me beautiful !!!

13. December began with the International Empowerment Day Awards given to about 20 Advocates and self-advocates who stood up for the Empowerment of Persons with Down syndrome. Christmas sessions for the Family that brought out the Fun element in all members of the family and A New Year session to help moms welcome 2021 with renewed Zest and vigor was the culmination of a Year virtually gone by . The 3rd Online medical camp was organized in association with the Parents Association of Down syndrome, Hyderabad (PADSH)
14. And the year beginning saw the first online THERAPISTS CAMP for kids under 4 years. Another feather in our Cap as almost 40 children were seen and counseled by therapists online. We are now planning a follow-up session for this Camp in the next few months.

# BHUTAN

## 2020 at Glance

### *Article 1*

Social workers with support from volunteers extended the intervention services through home visits to all children with disabilities enrolled at the center in Thimphu. When the severity of the pandemic arose, timely home visits were not possible, so it was virtually updated. Thus, ABS developed communication material as well as acquired intervention toys with support from UNICEF Bhutan and distributed as per the needs of the child in order for children to engage at home. Furthermore, social workers of ABS assisted parents in developing structured daily routine to practice at home. Parents expressed that it was much easier to communicate with their child through the pictorial book and spend more time together. Tenzin Yeemin and Jigme Choden are some of the beneficiaries with down syndrome. They are seen thoroughly engaged with help from the communication book and toys at home.

*Tenzin Yeemin, 7 years old studying the communication booklet*

*Jigme Choden, 11years old playing with the toys*

*Article 2*

Dorji Wangchuk a 12-year-old boy with Down Syndrome from Punakha is currently studying in class 2 at Lakhu Primary School, Punakha. He had to repeat classes due to his condition however he hasn't given up in learning. His parents encourage him to study despite their unsteady fiancé and strives to provide educational support hoping that he will be able to become independent in future. They live in a small hut and survive from the father's pension. ABS, Punakha supported by giving a seed money under income generation programme funded by ABS/BMZ/DAHW project to his parents for agricultural work in order to support Dorji and the family. They are also teaching Dorji the skills for farming in case he decides to pursue farming as his career in future. Currently Dorji is helping his parents expand their vegetable garden and they are generating income by selling the vegetables which has been helpful especially during the covid-19 pandemic.

*Dorji Wangchuk in his garden*

# MYANMAR

To look at a glance of 2020, everybody is struggling in the new normal life including us. However,we are continuing the MDSA(Myanmar Down Syndrome Association) actions by highlighting especially the health care, research, physical support for Emergency Response situations, empowerment of persons with Down syndrome, and training good citizenship for the political reform process in Myanmar.

To respond to the Covid-19 situation, we donated the basic needs and foods to the families of MDSA. For the health care, persons with Down syndrome were provided **flu vaccinations** in June 2020. MDSA is also implementing the **'Treatment of health problems** that lead to impair the mental and physical development', a programme which was the outcome of a research activity in 2019. Furthermore, we send our representative doctor to Inclusive Health Symposium on Feb2020 for future plan of health improvement .

MDSA could be able to participate and contribute to the **Research project** for “Opportunities for Health Care in Children with Down syndrome in the Regional Hospitals of Myanmar” with the cooperation of Yangon Children Hospital under the funding of the Government. As the impact of research, we have done research for 300 participants and the research is still going on.

To enhance the empowerment of the Down syndrome people, we initiated the ‘Job/Employment development” workshop in December last week 0f 2019 and we implemented the production of HandSanitizer.

Furthermore, we are able to produce a short film in cooperation with Ds-42 which illustrated the ‘We decide’ theme to display at the World Down Syndrome Day Global Video Event 2020.

As the milestone of 2020, our children were offered as the actors and actresses for advertising the car commercial program which is launched on Youtube now under the title ofMitsubishi Car Advertisement.

Moreover, the head of MDSA leads in the public event and talks in order to promote the social inclusion of people with Down syndrome. Although the pendmic time is restricted, MDSA has celebrated World Down Syndrome Day and other social events through social media.

By applying the good opportunities of virtual communication, we could increase the networking with other organizations . In 2020, MDSA did collaboration and cooperation with Local and International organizations such as Save the children, DSi, APDSF, MFPD and so on for promoting the role of people with Down syndrome in the community.

2020 is one of the biggest years in Myanmar as the election is running for the by giving voter

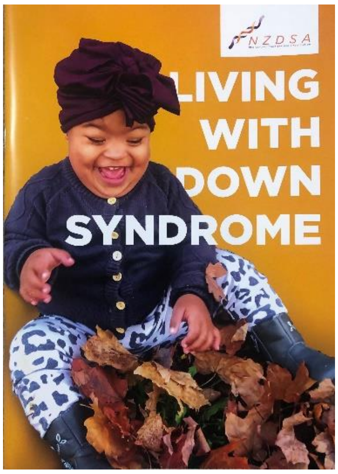
education, and support them to give vote safely in the Covid time.

To sum up, we were passing the struggling time with our team spirits in 2020. It is difficult to see the leaves and blossom of a tree, MDSA is currently the seed for the future of the development of people with Down syndrome .

Compiled and prepared by Mar Lar Phyu, Chairperson, Myanmar Down Syndrome Association

# NEW ZEALAND

The NZDSA was pleased to mark WDSD with the launch of the digital story *#We Decide* which was a message that people with Down syndrome wanted to share with the wider community.



The launch of the new website just before lockdown was invaluable as it enabled the NZDSA to proactively create a hub of information during lockdown so that our members could continue to access relevant and key information.

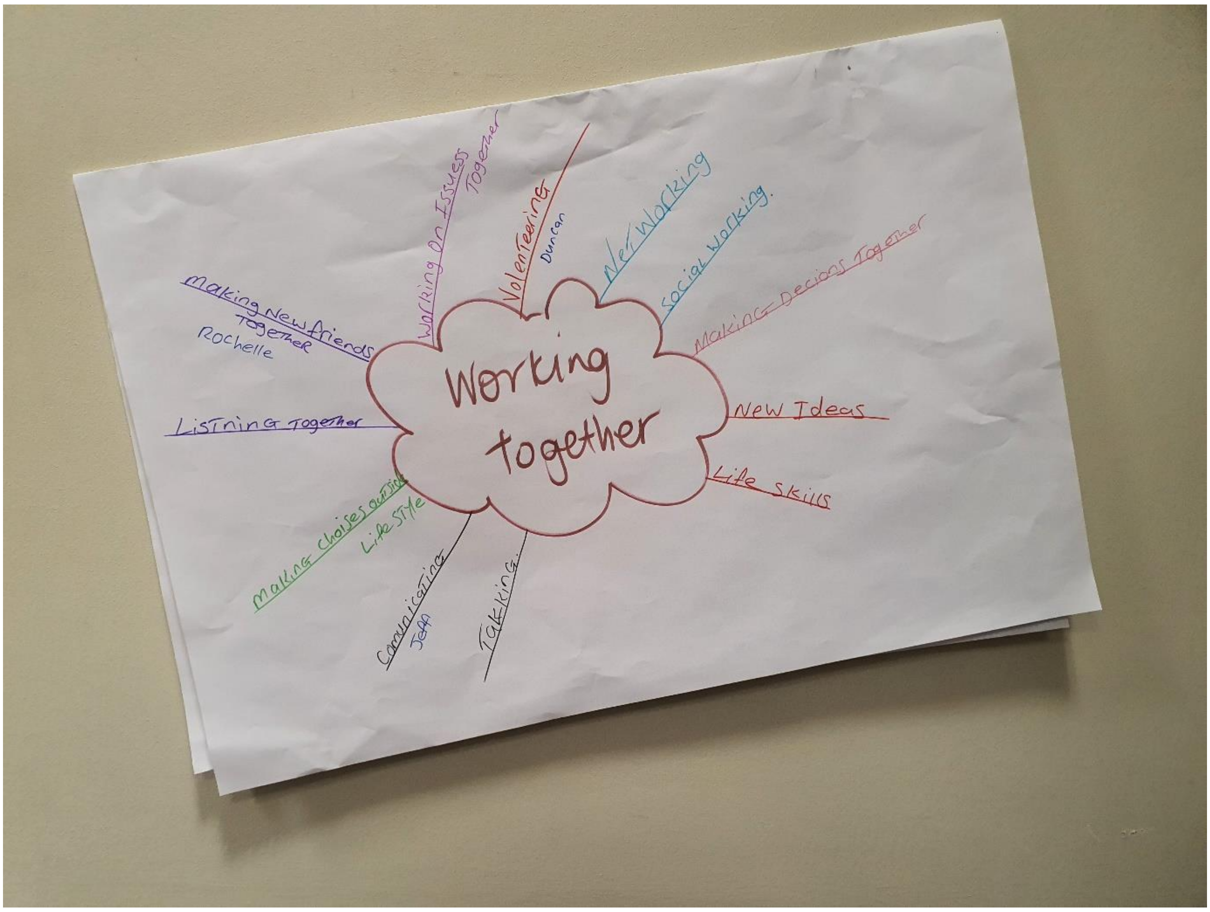
We also developed numerous online resources and updated the 'Living with Down syndrome' booklet

The NZDSA embraced the world of zoom during lockdown which enabled us to share information and connect with our members.

The NZDSA also researched how our community experienced COVID-19 which helped us to provide support and for systemic advocacy.

We were fortunate to have periods with no lockdown restrictions which enabled us to host advocacy and education Funshops for self-advocates and to gather for social events and Christmas celebrations.

Self-Advocates at November 2020 Funshop



Feedback at a workshop

End of year social gathering for members in the Mid Central Region.

The NZDSA continues to provide our core services and advocates on various platforms. We also provided education to our members in the MidCentral region so that they are empowered to engage in the system transformation prototype, Mana Whaikaha.

We would like to wish all the groups in APDSF the very best for 2021.