



April 2021

President Speak



How time flies. It seems like the first wave of the pandemic just hit us closing everything around us and now this fresh wave is threatening to do the same. We all thought that come 2021 and life would be normal – like the pre-corona days.

But then Corona is back – and it seems so is the lockdown. However, we as a region have been active during the entire period. And this edition of the newsletter is testimony to that.

We have all celebrated World Down Syndrome Day in our style. And I am glad that this edition of our e-News stands out like a ray of hope that come what may, we know how to live our lives to the fullest.

Persons with Down syndrome have always been tough and during this entire period they have shown us that given opportunities, they can also turn the tide in their favour.

We wanted to release this newsletter on the 7th of April which is celebrated as World Health Day. So here is wishing all of you Healthy days ahead.

Regards

N. Ramachandran

President – APDSF

Australia

Throughout March we shared 21 stories in the lead-up to 21 March, and this year's stories were all by people with Down syndrome. Our final story was from Michael Sullivan, our Down Syndrome Advisory Network Chair and Australian representative for Down Syndrome International.

Michael is passionate about being a voice for people with disability and shared why he strongly believes people need to speak up about issues that are important. You can read Michael's message here:

<https://www.downsyndrome.org.au/day-21-michael-sullivan-international-advocate/>

The Australian Down syndrome associations also raised awareness and funds throughout March with our national 'Lots of Socks' campaign. This year our sock design was co-designed by artist Peter Rowe and featured Australia's Great National Wonder, the Great Barrier Reef.

World Down Syndrome Day was celebrated in Canberra with a Parliament House Morning Tea and the launch of our new national Health Ambassador program.

The Health Ambassadors are a group of people with Down syndrome who inform others about how to communicate with and include people with Down syndrome in health conversations. The Ambassadors are already taking their job very seriously and have been busy making sure our leaders are hearing their message.

You can find out more about our Ambassadors here:

<https://www.downsyndrome.org.au/advocacy/health-ambassadors/>

Health Ambassador Naomi Lake shared this important message for World Down Syndrome Day:

<https://www.facebook.com/DownSyndromeAustralia/videos/2954985631490012>

India

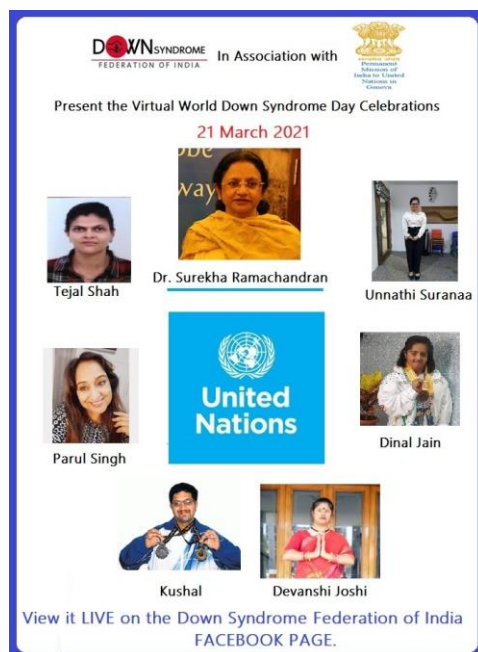
India is a land of Diversity...and nothing can or will deter us from our goal to create an inclusive society for persons with Down syndrome – not even Corona. The lockdown did not deter us and we went ahead with all our plans and completed our goals. India has been connected despite our cultural and other differences...language has never been a divide and we have kept India together then and now.

2020 will be remembered as the year that changed the world. We were ready to celebrate WDSD 2020 with a bang. Lots of activities were planned, buildings lit up, various programs planned across states and the WDSD celebrations at the UN with Self-advocates, parents and the President of DSFI, Dr. Surekha Ramachandran as guest speakers. But it was not to be. The lockdown began and WDSD 2020 was relegated to a damp event.

We wanted WDSD 2021 to be a grand event. WDSD is celebrated globally in order to spread awareness about Down syndrome. And this year, we are glad that the Down Syndrome Federation of India was able to reach across the length and breadth of the nation in our bid to spread the awareness. Here are a few things that we did as a part of our celebration

1. At the UN

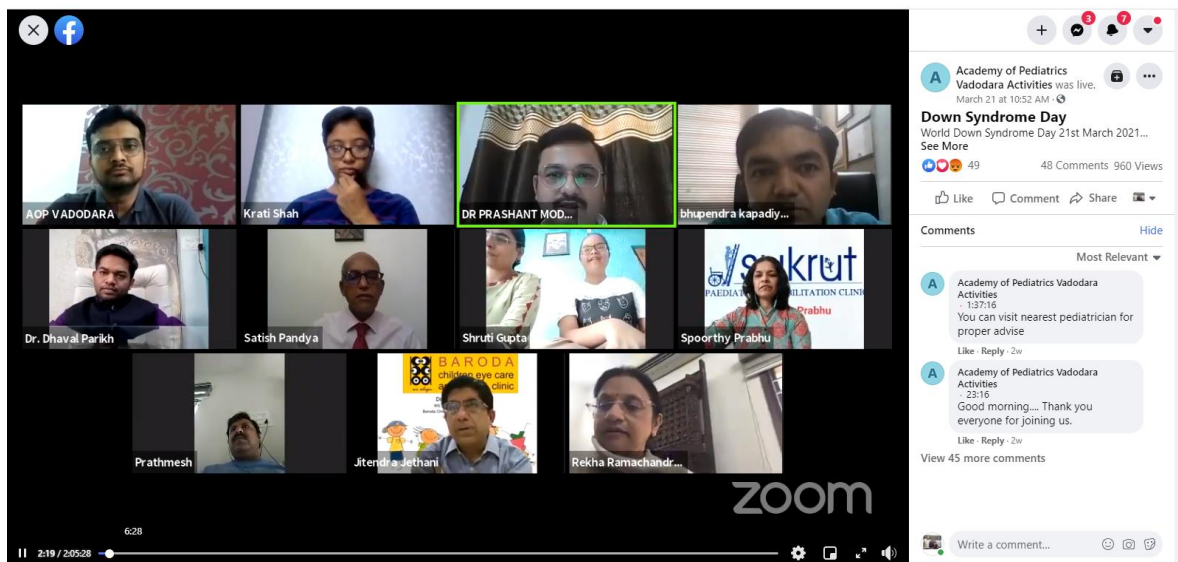
We celebrated WDSD 2021 virtually over Zoom in association with the Permanent Mission of India at the UN Office in Geneva. Ambassador, His Excellency, Shri Indra Mani Pandey was our main guest who was with us throughout the meeting that lasted almost One and a Half hours . The special speakers on this occasion were our self-advocates who stood up on that platform, all bold and confident, and talking about their lives and their goals. Dr. Surekha Ramachandran, President of DSFI spoke about how India has progressed and is one of the best places to be in for persons with Down syndrome. Our parents spoke about their journeys and how they brought about changes in the lives of many parents.



2. Support of the Medical Community

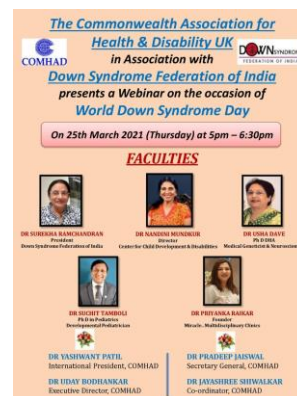
We have been actively seeking the support and able guidance of the medical fraternity. We have had multiple events where we have tried to involve the medical community to help support our cause. One such event was held at Surat, Gujarat and another event at Baroda in Gujarat. Our online platforms have been a real boon for us to promote Down syndrome and seek the support that we all need for our loved ones with Down syndrome.





3. Joining hands with COMHAD

COMHAD or the Commonwealth Association for Health and Disability is one of its kind organization in the commonwealth for the betterment of persons with Disability. The Down Syndrome Federation of India joined hands with COMHAD to speak about Down syndrome and the various platforms available for our parents and self-advocates to express themselves. Dr. Ramachandran spoke about Down syndrome in India and the role that the medical community could play in the betterment of their lives. Attended by participants from across the commonwealth countries, the event was a major eye opener for many of the participants.



4. Connecting with Fernandes Hospital, Hyderabad

Fernandez hospital is a neo-natal service provider from the Indian city of Hyderabad. They have a Child Care Center where they would like support for taking care of persons with intellectual Disabilities. They wanted to join hands with the Down Syndrome Federation of India to form a guideline of sorts for the Early Intervention and Care Center. It was a wonderful opportunity for DSFI to connect them with the local Parent Support Group and help them avail of the services offered including health and therapies from Experts.



5. Future Caregivers

The importance of Caregivers can never be understated. And a professional caregiver can definitely be a wonderful asset. For WDS 2021, DSFI got connected to a nursing college from Bangalore who wanted to learn more about Down syndrome. It was a well attended session and the students asked questions that would help them provide caregiving for persons with Down syndrome. The Federation has been trying to spread information across groups so that we are able to create an inclusive society.

6. Sporting activity across the country

An event was organized across the country for the better health of persons with Down syndrome. Called Taare Zameen Par (Stars on Earth), persons with Down syndrome

were expected to do any one of the three physical activities – Running, cycling or exercising on a daily basis for 15 days from 1st to 15th of March. All participants used the Strava app to record their activities. At the end of the period, they were given medals and tee-shirts to boost their morale. And it indeed did help them feel a lot more healthy and motivated to continue.



7. Other events to celebrate persons with Down syndrome



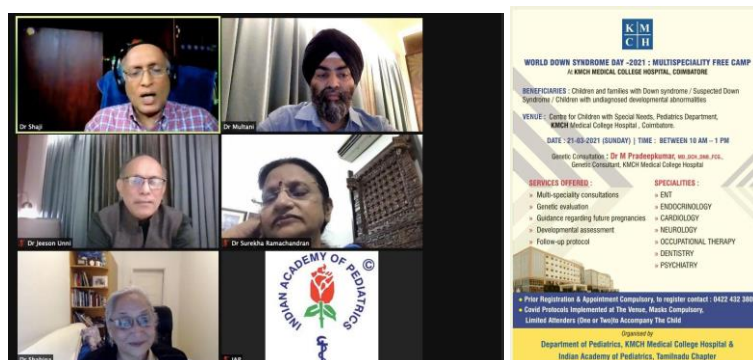
Cake Cutting in Jalandhar



Release of film Aahaan about Down Syndrome



Fun Sessions



Session with the Indian Academy of Pediatrics



Schools for persons with Special Needs

8. Cloud 9 Hospital Tie-up

We have tied up with Cloud 9 Hospitals which is a major player in the Indian hospital scenario. They will be providing services at a subsidized rate for persons with Down syndrome anywhere across the country.

WDSD 2021 has been an experience to remember. Thanks to the online forums, we have managed to spread the word far and wide. We do realize that getting bogged down by a situation, any situation is easy. But we need to learn to deal with and address issues that crop up every day with a sense of calm. It is this confidence and never die attitude that keeps us all strong and determined. This WDSD just proved how we can deal with any situation that life throws our way.

Indonesia

Since the global pandemic a year ago... ISDI had been keeping off all activities in the Center of Hope ISDI. We had been in lockdown since March 2020.

But 2021 brings new hope for the coming new normal. We are terribly lucky and grateful for some sponsors who has given so much attention to our cause... and that is to elevate people born with Down Syndrome in Indonesia to a new level of appreciation and awareness... which have seen us making a few milestones:

1. Cooking and baking lessons like a pro with Oxone Kitchen Ware.
2. Working experience in the offices of Makarim & Taira S. Law & Counsellor's Offices.
3. Working experience at the international airport of Soekarno- Hatta, Jakarta as welcoming crew at the Priority section of domestic departure.
4. Performing contemporary dances in youtube.
5. Fashion shows for local designer houses.
6. Photoshoots for renowned magazines.
7. Selling cookies.
8. First Karate program in Indonesia for Down Syndrome.
9. Gong man for the Para Games Opening Ceremony in Jakarta, Indonesia.
10. Was honoured to participate in supporting by singing and reading poetry at the National Music Day in Indonesia on 9th March 2021... being the first disable people to be chosen...

Oxone Kitchen ware, who has been teaching us cooking and baking for two years has paid us tribute by putting up a huge billboard on a strategic and busy highway for the whole of March...as well as cooking competition...in celebrating the World Down Syndrome Day..... a trully incredible gesture. And Makarim & Taira S. Law & Counsellor offices is helping us with a painting competition for the World Down Syndrome Day too..

The month of March has given us so much blessings and we feel honoured.

Happy World Down Syndrome Day to all happy people blessed with Down Syndrome, their families and all those who cares and support them. God Bless...



Mongolia

Down Syndrome Association Mongolia (DSAM) very successfully partnered with JICA (Japanese International Cooperation Agency) this year to celebrate World Down Syndrome Day 2021.



10 thousand copies of upgraded edition of “Down Syndrome: Guidebook for Parents” and 1500 copies of Reference Set to assist teachers, medical doctors, social workers and volunteers working with children with Down Syndrome were published and distributed nationwide to all 21 provinces of Mongolia and 9 districts of the capital city Ulaanbaatar in March.



Both, the Guidebook for Parents and Reference Set have been written in close cooperation with the Professionals' Support Group consisting of highly qualified specialists (medical

doctors, special education teachers, psychologists, speech pathologists, social insurance and social welfare officers) who have an extended experience in working with children with Down Syndrome locally.



Moreover, during this pandemic period our Association produced 8 online lectures and video contents for our members, covering key aspects of Down Syndrome, and posted all of them on social media channels.

Last, but not least, the first time in Mongolia, a person with Down Syndrome is starring in a movie co-working with famous professional actors and producers.

The movie titled “Trio” will be released by the end of 2021 and aiming to participate in the international film festivals in ip coming year in order to raise public awareness of not only Down Syndrome but also to correct the misconception of the term “mongolism” and “mongoloid”.



Last but not least, the first time in Mongolia, a person with down syndrome acting for a movie with professional and famous actors and producers. The movie title called "Trio" will be released by the end of this year and aiming to participate in the international film festivals in 2022 in order to raise public awareness of not only Down Syndrome but also to correct the misconception of the term "Mongolism and mongoloid".

P.S. Please visit our page **DSAMmn** on Facebook for more visual information.

UN WDSO Conference 2019 in Geneva. Speech of Mr GANZORIG Vanchig, Chairman of Down Syndrome Association Mongolia. March 21, 2019

Leave no one behind

Ladies and gentleman! Good morning! A happy 2019 World Down Syndrome Day!

I am Ganzorig Vanchig, a Founding Member and a Chairman of Down Syndrome Association Mongolia!

I would like to thank The Permanent Mission of India to United Nations, and Asia Pacific Down Syndrome Federation for inviting me to the "WORLD DOWN SYNDROME DAY" at the United Nations, Geneva. It is my honor to be here on this very special day.

I have just come from Special Olympics Summer World Games from Abu Dhabi, United Arab Emirates. Nearly 8000 determined kids, adults, and athletes participated in this great movement. Of course, hundreds of people with down syndrome too. Mongolia send 28 athletes and 3 of them were athletes with down syndrome. Our three kids won 1 gold medal for swimming and 2 silver medals from fierce table tennis competition. They did it. They proved that people with down syndrome have full potential if we provide equal opportunity to them.

A few years ago the world had problem of apartheid. Then gender issue raised. Now humankind has inclusion challenge for the determined people. There are over 200 million people with intellectual disability in the world. Every day over 100 thousand new babies are coming to the world. According to the statistics, there is one baby with down syndrome in every 700 babies born. This means we have millions of people with down syndrome. But where are they? They die early or they have been hidden at home. How do they survive? Do

they work? What do they do? These are our fundamental questions and Down Syndrome Association Mongolia's key challenges.

We, Down Syndrome Association Mongolia, founded 11 years ago. Our mission is to make people with down syndrome are fully included members of Mongolian society and more importantly valued tax payers. In order to implement this mission, we focus 3 main pillars. These are health, education, and employment. The biggest challenge is employment. Because there is no place for them after completing their schools. While kids are growing and becoming adults, parents are getting older. It means that hundreds of people with down syndrome are forced to live alone after their parents and required to feed and socialize themselves. There are no such service and facilities in Mongolia so far. The only solution to this problem is employment indeed! We must provide equal employment opportunity for them to be economically independent!

Down Syndrome Association Mongolia established vocational training center and already started preparing young adults with down syndrome as work force to the labor market. Work is life, happiness, energy, and joy to them. While working they learn new things and get lots of new friends. They always appreciate to hear thank you word from others. In fact, their employment goal is not really get salary but to make people happy. I will show you short video after my speech.

Shangri-La Ulaanbaatar hotel is our first employer to accept hiring people with down syndrome. Parents and teachers are very supportive. Public too! But generally speaking, there is a need to education private sector, employers, and some of our family members, friends and colleagues. Still some people discriminate and others only show empathy. But down syndrome communities' needs are to be accepted and to enjoy and protect their human right! I met many Mongolian business executives to raise money and to find employment opportunities for people with down syndrome. I never forgot what one of them told me. She said that my company image is very high and my product brand awareness is great. Therefore, I don't want to ruin my company and product reputation by having association with down syndrome. I just left her room and thought people with down syndrome is not our society's problem. The real problem is what we call ordinary people. Those 200 million people with ID is not a problem at all. 7 billion people, I am, you are, we are the problem and also we are the ultimate solution. Hence, in order to build positive attitudes towards people with down syndrome, we must work together even more closely to generate resources, strengthen leadership, and build capacity. More importantly, we have to work with professional media as close as possible in order educate and inform public and to treat our social syndrome.

APDSF as a body is working towards the betterment of persons with Down syndrome in the Asia Pacific region. APDSF has influenced a lot to Mongolian Down Syndrome Association to create the first valued tax payer to the government. Some people escape from tax and try to hide their income, but our guys begging to pay tax. Isn't it great heart and endless love? Actually, I see the formula of mankind's happiness and solution to fix current complicated world affairs from the heart of people with down syndrome. Let us enable their identity! In return they will empower our identity!

Fish cannot survive without water. We are fresh water for our own determined community. The world speaks many languages. But we speak only one language. That is LOVE. Most people believe in the God. To me, inclusion is the greatest religion and my only God! Let us leave no one behind!

Thank you very much for your attention!

Let us watch our short video about vocational training center and dream of young adults with Down Syndrome! Thank you BSP production team for supporting us and making this amazing video.

https://www.youtube.com/watch?v=7nZSP6D6v_4

Singapore

Down Syndrome Association (Singapore) celebrates World Down Syndrome Day 2021

DSA held its first World Down Syndrome Day celebration online amid the COVID-19 pandemic and safety management measures. In its 16th edition, the 'live' event was co-hosted by our very own members, Allan Cai and Judith Teo, together with volunteer Brynner Janato. We were privileged to have Mr. Edwin Tong, Minister for Culture, Community and Youth and Second Minister for Law grace the event at our DSA Centre @ Bishan Junction 8, and the support of grassroots leaders from Joo Chiat CCC and Siglap South CCMC.

Together with our online community, viewers were treated to a Zumba workout led by our Zumba group members and youths from Siglap South Youth Network and a montage of past events and activities to recollect over the past year. The 1.5 hours live show also featured an array of performances, a trivia quiz and the launch of a short film titled 'Not Your Ordinary Love Story' by Viddsee. It was heartening to see so many of our supporters tuning in and engaging with us during the live show.

In a show of support for DSA's 'Soar High' campaign, James Cook University engaged their students in a kite-designing activity at their campus while students from ISS International School initiated a series of fundraising activities.

Through the effort and support from all our donors, sponsors, members, and volunteers, over \$170,000 was raised through this event for our Down syndrome community! We are immensely thankful for everyone's generous contribution and participation, and we look forward to your continued support in our charitable endeavours.



Minister Edwin Tong shares that “our persons with Down syndrome need our active participation to make Singapore a safe and supportive home for them”



Minister Edwin Tong putting his creative touches to the DSA Kite Kit with DSA Member Alyssa.

From left to right: DSA Ambassador Judith Teo, Volunteer Brynner Janato and DSA Ambassador Allan Cai hosted the 'live' event on 21 March 2021



DSA Ambassador Judith Teo, welcomed Minister Edwin Tong to the celebration held at DSA Centre





From left to right: Co-host Allan Cai (DSA member), Event Photographer Reuben Khanal (DSA member), Co-host Judith Teo (DSA member) and Co-host Brynner Janato (DSA volunteer) at the 'live' event held on 21 March 2021

The Covid-19 Pandemic severely impacted the activities of most government institutions, private establishments, and of non-governmental organizations in 2020. The situation has improved since January 2021, where many restrictions were gradually relaxed, but still under strict health advices. Schools had to adopt virtual learning and online learning systems, but there were many limitations outside the urban areas. Schools started to re-open for in-person learning, under strict health guidelines, in mid-March 2021. As a country the vaccination program is steadily moving ahead where vaccines were imported. Currently, the vaccines are administered to people above the age of 60 years in Colombo, the district which was severely impacted by the pandemic.

WORLD DOWN SYNDROME CELEBRATION – 21st of March 2021.

JRCDS had series of discussion with The Rotaract Clubs in two districts and with the National Youth Services Council to conduct medical camps, counseling, art therapy projects in three districts. However, this program had to be postponed as the local health authorities did not grant permission to implement the projects in-person.

Many parents are requesting us to establish a home for children with Down Syndrome.

But we cannot run a home for DSC as our objective is to serve the DS children scattered in all corners of the country. Our main target is to form 100 or more DS welfare clubs especially in rural areas. We have few Day Care Centers confined to Colombo and Kandy districts, serving children with special needs.

Plans for the year 2021 and post-pandemic recovery

JRCDS will continue/ re-start the work planned before the pandemic, as follows;

1. Main task is to form Down Syndrome welfare club in many parts of the country .
2. Implement training programs for pre-school teaches in the island in order to give training to accommodate children with DS in their schools .
3. Counselling programs for parents
4. Give an awareness program for school children.
5. Printing and distribution of medical record books and diet chart books .

But all depends on the progress of Covid-19 pandemic recovery in the country .

There were several independent organizations throughout the country with better infrastructure, financial resources and human resources who conducted many welfare activities, providing a helping hand to people in need, during the pandemic. However, in many places there was a need for coordinated effort for a larger impact. Hence, a post-pandemic assessment/situational analysis needs to be conducted to investigate

- how people with DS were impacted during the pandemic
- What worked well, and what didn't in-terms of addressing the issues of children with DS during the pandemic
- What needs to be changed, both short- and long-term, to better facilitate the needs of people/children with DS during the post-pandemic recovery phase
- What institutional frameworks and/or policies are needed for a coordinated effort in a future pandemic-like situation.



As a part of WDSO 2021 Initiatives: Emirates Down Syndrome Association organized “Enarat Virtual Conference”.

Emirates Down Syndrome Association organized Virtual Conference on the occasion of the World Down Syndrome Day 2021, on Saturday and Sunday 20-21 March 2021, under the title “Enarat Virtual Conference”.

The conference brought together an elite group of scientists, researchers, and specialists in various fields related to people with Down syndrome.

The conference consisted of (17) virtual sessions conducted in “Arabic language”, the participation was free of charge for all, and (375) participants from across (21) countries attended the conference.

The conference was streamed live on YouTube, the recorded sessions are now accessible using the link: bit.ly/3lCwAr6



- **In collaboration with Emirates Down Syndrome Association, the UAE Towers (Global Icons) Honored the World Down Syndrome Day 2021**
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- **Burj Khalifa and Burj Al Arab lightened up in blue and yellow**
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- People with Down syndrome, their families, advocates, and specialists enjoyed the amazing look of Burj Khalifa and Burj Al Arab lightened up in blue and yellow.
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- This came in the celebration of the Emirates Down Syndrome Association of the World Down Syndrome Day, which falls on March 21 every year.
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- In addition, people with Down syndrome, had an amazing time and experienced the magic of Dubai Aquarium and Underwater Zoo and the legendary views from At the Top, Burj Khalifa at the same day Sunday 21st March.
- Dr. Manal Jaroor, EDSA chairperson, praised the strategic partnership with Emaar and Jumeirah Group, and highlighted the great impact of such event on the social awareness about people with Down syndrome, locally and globally.
- *Watch Burj Khalifa WDSN Projection using the link:
<https://www.instagram.com/p/CMsEISAh2bL/?igshid=lnkiq771caxk>
- *EDAS visit to the top of Burj Khalifa and Dubai Aquarium and Underwater Zoo:
<https://www.instagram.com/p/CMtldLinXiz/?igshid=1qsgsnwjm4epz>
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ينظم مجلس شرطة دبي الطلابي
بالتعاون مع جمعية الإمارات لمتلازمة داون
Dubai Police Students Council at Hemaya International Center
in cooperation with Emirates Down Syndrome Association

ورشة تدريبية بعنوان
workshop entitled

اليوم العالمي لمتلازمة داون

World Down Syndrome Day

الدكتورة نادرة البورنو
Dr. Nadera Emran Alborno



اضغط هنا
Press Here

الثلاثاء 23 مارس 2021
Tuesday 23 March 2021
11:00 AM



#WDS21 #اليوم العالمي لمتلازمة داون



#WDS21 #اليوم العالمي لمتلازمة داون

- **Emirates Down Syndrome Association (EDSA) conducts awareness sessions on the occasion of WDS2021**
- Starting from 20th of March and until the end of the month, EDSA is conducting several virtual awareness sessions with government and private institutions. The sessions targeted the internal staff of these institutions, and focused in explaining about Down syndrome, their abilities, and the importance of fully include them in the society.