July 2021
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PRESIDENT SPEAK

It is time for the next edition of our newsletter and we are glad to inform you that more countries have provided an insight into the activities that they have organized.

2021 also seems to be going the way 2020 did – indoors for most of our loved ones with Down syndrome. It is however essential that we provide them with a platform to express themselves and keep them occupied.

I am happy that there are so many takeaways from our members this time for keeping self-advocates busy. The APDSF e-News is a source of information sharing and learning and this is what it is proving to be.

The APDSF AGM, as informed to you by mail is being planned for the first fortnight of October and I am looking forward to seeing you all virtually. Details pertaining to the AGM will be shared with the group closer to the event.

The pandemic seems to be waning, however we cannot throw caution to the winds. We need to ensure that proper protocols continue to be maintained.

Till the next newsletter then, Stay Safe and Healthy.

Regards

N.Ramachandran

President - APDSF
Supporting the Down syndrome community and providing opportunities for people to connect has been a priority for Down syndrome Australia during the pandemic. The resilience shown during these tough times has been incredible. People with Down syndrome have also embraced technology and adopted innovative ways to connect over the past 18 months.

During this time, Down Syndrome Australia have worked with people with Down syndrome to build skills and capacity in Leadership. With our Down Syndrome Advisory Group, DSA developed a 5 module training program called Becoming a Leader. The modules cover Meetings, Rights, Public speaking and Leadership. In the final session the group come back together to deliver a short presentation to their peers about being a leader and to talk about the goals of their leadership plans. The training has been delivered online, with one session a week for 5 weeks and also a small number of groups have been held as face to face sessions. To date, 35 people with Down syndrome have completed the training.

Down Syndrome Australia has also recruited 10 self-advocate Health Ambassadors.
Each of these individuals has a story to tell about their journey within the health care system and they want to share this information with health professionals to ensure that in future people with Down syndrome get access to better quality care through inclusive communication. To set the Health Ambassadors up for success, they completed training on public speaking and presenting. An 8-week, 1 hour per week, online course, delivered by a professional in the industry. Each session was followed up by 1 hour group chat and discussion and critically appraising each other. Each of the Health Ambassadors now has their own speech to present to health care workers and students about inclusive communication.

Students and professionals seeing people with intellectual disability as authoritative sources of information and knowledge will create a significant shift in attitudes and understanding.
ABS observed World Down Syndrome Day by bringing together parents/caregivers of children with disabilities from five districts (Thimphu, Punakha, Sarpang, Dagana, and Chhukha) with Mr. Aditya Tiwarl, Social Reformer/Parent from India. In 2016, he received a Certificate of Excellence for becoming the youngest single parent to adopt a child with Down syndrome. Mr. Aditya gave valuable insight on children’s diet, social skills and activities of daily living skills.
In addition, ABS staff at Trashigang initiated to raise awareness on down syndrome by involving students of Draktsho Vocational Centre for Special Children and Youth. Sport competition among the children with disabilities including children with Down syndrome was held. To commemorate the day, a total of 130 participants attended including students of Draktsho, instructors, monks and local community members.

Similarly, through social media and a website, awareness about Down syndrome was raised. ABS plans to expand its activities in the future to include parents and children/persons with Down syndrome all around the country. The goal is for parents to find comfort in sharing their stories and to be motivated in participating in activities/services.
DID YOU KNOW?

1. Down syndrome is a genetic condition where a person is born with an extra chromosome 21; which means they have three rather than two copies of the 21st chromosome also known as trisomy.

2. They have a total of 47 chromosomes. They have got that something extra :)

3. Babies with Down syndrome have low muscle tone known as Hypotonia which is why it will take them a little longer to talk, walk and eat the same foods as others. They work extra hard and they get there!

4. Persons with Down syndrome share similar features.

5. We prefer ‘person first’ language. A person has/with Down syndrome. Not a Down syndrome child because Down syndrome do not define who they are.

6. Person with Down syndrome can lead happy, independent and successful life. Become TV stars, learn to drive and even climb Mount Everest. Don’t count them out!

7. Person with Down syndrome aren’t ‘always happy’. They have feelings just like everyone else.

8. Down syndrome is named after John Langdon Down, the British doctor who fully described the syndrome in 1866.

Information from @Double Helix
Bahrain Down Syndrome Society is starting a new project which is to prepare a new curriculum in Arabic, set for Down Syndrome children’s. The curriculum refers to the knowledge and skills that students expect to learn, which includes educational goals, books, materials, videos and presentations.

The importance of the curriculum

- To help students with down syndrome to develop their integrated and comprehensive aspects, such as; (mental, physical, social, emotional and linguistic) so that this growth contributes to the psychological compatibility of them and modify their behavior.
The curriculum is an evaluation tool and a reference for educational objectives and measures the current performance of students.

- Raising the efficiency of specialists and staff in the field of training and rehabilitation of Down Syndrome.
- Preparing the first specialized curriculum for down syndrome in Arabic that includes different aspects of growth at different stages of life.
- The existence of a curriculum will enhance the training needs of the Down Syndrome.
- Introducing and spreading awareness of down syndrome when conducting seminars and training courses for the curriculum.

The curriculum will focus on areas and set of objectives, implementation procedures and tools used:

- Academic skills,
- Life skills,
- Autonomy skills,
- Movement imitation skills,
- Visual cognitive performance skills,
- Fine movement skills,
- academic Functional skills
- Pre-vocational skills
- Language skills
CHINA

Under the severe situation of the epidemic, we can not meet each other, but we can still communicate through newsletters. Thanks for this opportunity to make us feel together. We hope all the countries can overcome the threat by the pandemic of Covid-19 as soon as possible, and everyone will be safe and healthy.

Up for Down’s——A re-established organization

Ten years ago, we were stuck in the sadness. But now, after taking the children to the outside to experience the beautiful nature, we have been heartened. During the recent years, we try to practice self-advocacy, farming experiments, and at the same time, to heal physical and mental health of our parents, children, volunteers.

Up for Down’s has carried forward under a new situation, serving as a bridge to fill the gaps between our country and the developed countries, with the ultimate goal of holding World Down Syndrome Conference in China.

Up for Down’s two-year plan: 2021.3.21-2023.3.21
1. All members complete the task of physical and mental health by frequent healing.
2. Start Hangzhou farming experiments;
3. Continue to translate Down syndrome materials as planned.

The origin of Up for Down's (Richard's creativity):
Down’s means down in English. Up for Down’s cleverly adopts the concept of opposites between up and down. What do we arise up for? To serve the Downs. (U.F.D. is the abbreviation of Up for Down's).


The origin of "Ding Tang" (Tian's father Xiaohui Jia's creativity):
English name U.F.D., translated into Chinese as "Ding Tang", these two characters were created by Tian’s father. “Ding” means tripod, an ancient Chinese vessel with three legs. We are the legs of the tripod, supporting Down’s, which perfectly interprets the meaning of Up for Down's.
Chinese ancient tripod. 

Jia

Tian and his father Xiaohui

The meaning of the U.F.D. flag (Designer Yu Ling):
Flag itself is an energetic picture, which expresses hope and love. Pink represents love, lotus represents luck, yellow represents hope, the stars in the background represent partners across the country, and the three yellow stars in the middle represent children, parents and volunteers.

10th Anniversary of the group
On 21st March 2021, we gathered together in Shanghai to celebrate the successful conclusion of the original group. At the same time, the new leadership team took over U.F.D. flag and we officially entered a new stage.

During the Meeting, Lena Ye, the founder of U.F.D., reported the achievements of the past decade:
1. Delivered talents to the country: Jianhai Li, deputy director of Down Syndrome Committee of China.
2. Joined Asia-Pacific Down Syndrome Federation in August 2019 and formed a partnership with Down Syndrome in Asia-Pacific region;
3. Established contact with the organizer of the World Down Syndrome Conference, and submitted an application for intent.

Ping Zhang, Director General of U.F.D.
U.F.D. Flag Award Ceremony

Jun Yang (leader of the first-generation parent committee), and Bokai Zhou (co-sponsor of the group), gave the U.F.D. flag to Ping Ying (Deputy Director General) and Chunxia Ge (national tour supervisor).

Northern leader Lin Li received the flag in advance; it was displayed at the event in Dalian on 21st March; Lena Ye personally escorted the flag to Guangzhou and gave it to Southern Leader Yahui Liu. Finally, Ping Zhang, the director general of U.F.D., delivered a sincere speech, which officially marked the end of the first 10 years and also means the beginning of a new stage--U.F.D..
Yahui Liu, Jia Yi and Guangzhou parents received the flag, and grown up Zixuan

U.F.D. flag flying under the beautiful blue sky in Dalian
After the meeting, parents, children and volunteers played African drums and danced cheerfully with MaoLv and Vivii.

During the bonfire party, with crude lights, everyone gathered together to watch the children perform Ukulele, sing, dance and other programs, we applauded each child. Finally we let off Kongming Lantern, and watched the light go away with infinite blessing...

During the game:
Farming experiments

The goal of the farming experiment: to have an intimate contact with the land, learn farming, and accumulate experience.

Team leader Rui Feng and deputy team leader Xiaonv Zou arranged parents and children to plant and pick vegetables, so that everyone can understand how various vegetables grow and gain knowledge while playing.

Team leader Rui Feng climbed up and made a fence. Really hard work.
Harvested fruits and vegetables:

Physical and mental health healing

Health is the capital of the revolution. U.F.D. is not eager to achieve goals at the beginning. We first focus on the physical and mental health of all the members of the group.
Stay Healthy & Explore our uniqueness!
The Hong Kong Down Syndrome Association is now making use of the social media to encourage people with Down syndrome, other intelligence disabilities as well as people with special needs to keep healthy and explore their uniqueness.

Oral Hygiene Training Video
People with Down Syndrome and Intellectually disabled persons are at much higher risk of suffering from poor dental health resulting in loss of their teeth in early adulthood. This seriously impacts their quality of life & social acceptance. There are not many diseases that can be preventable, yet poor dental health is one that can be completely prevented through establishing good oral hygiene in the daily practices of Tooth Brushing. So, we are going to proceed an Educational and Motivational Video for people with Down Syndrome and other Intellectually Disabled Teenage Young Adult to ‘Self Improve’ Oral Hygiene Habit to prevent Dental Disease that leads to tooth loss with our Dental Advisor

The video is going to be shoot in July with celebrity, Ms. Kandy Wong. Let's Stay Tuned!
**Human Library Hub**

On 21st March, The World Down Syndrome Day, The Hong Kong Down Syndrome Association organized an online Human Library Event to let you all know more about the unique life stories of people with Down Syndrome and their family. It’s believed that each individual has their life and experience. Therefore, the Association develop Human Library Hub and committed to inviting more members to join the Human Library Hub and be part of it. It is hoped you all will be impressed and inspired by those “Books” as well as their chapter of life. Let’s explore your unique one!

Visit our Human Library Hub:
2021 began on a good note for all of us. We believed that we had gotten some control over Corona and we would be safer now and things could get back to normal. But we realized very soon that we were wrong in thinking so.

India as you all know was one of the worst affected due to the second wave. Our primary aim during these trying times has been to keep our children safe. However by safe, we realized that being inside also meant having to keep them occupied productively. The Federation with support from its various Support Groups was able to do this too. Below are some of our activities that kept our Self-advocates busy during the lockdown.

1) Rekha Maa’s Magic Mantras – After the success of our Mantras earlier, parents wanted us to provide our self-advocates with some activity that could keep them occupied for some time at least during the day. Ranging from physical activities to arts and crafts, our self-advocates proved that nothing can deter them.
A MOMENT OF PRAYER

Today @ 6 P.M. Let all of us PRAY TOGETHER. From our homes - for the well being of everyone. It’s time to bring out POSITIVITY.

Say it with FLOWERS

On 21st of April, we want our self-advocates to Express with Flowers. Let them express their love for life, with Flowers as the theme. It can be a song, a painting, a garland - anything to tell us all how precious and beautiful life is...

So the mantra for the 21st of April is FLOWERS!

Self-advocates - We are waiting for your Flowers. So WhatsApp it to us - 98400 60817 before 7 P.M. tomorrow (21 - April)

Teach your Children to express themselves

Without speaking, Teach your children to reach out to you By just acting... Words, Actions, Pantomime... Just ENJOY

This Magical GAME!

WhatsApp us the 30 SECONDS video - 98400 60817 (by 7 P.M. please)

ALL THE BEST!
Story Telling Sessions – Our Self-advocates actively participate in story telling sessions which also helps enhance their cognitive abilities. This session takes place every Tuesday and is an eagerly awaited one.

Rendezvous with Self-Advocates – Wednesday is the day to meet up with our Self-advocates. They come, they talk, they share and do they participate with all enthusiasm. Sessions were held to ask them about various aspects of themselves including likes and dislikes.

Session with Experts: Again DSFI started a session for parents where they can clarify their doubts with the experts. These are experts from various fields – both medical and non-medical.
Financial Support for persons with Down syndrome: During these tough times, we also had requests for financial support for some children for their surgeries. And thanks to the support of Donors, the Federation was able to support some surgeries across the country.
The Lockdown has brought to the fore the tenacity and strength of our self-advocates and their families. While we hope and pray that the situation turns for the better, we are also aware that our self-advocates will be able to adapt themselves, whatever the situation be
Good morning, hope everyone is well and adjusted to the new normal and wait patiently for this horrid pandemi to go away.

We, ISDI, can do nothing but continue with the program via Zoom link, video call and what not to keep our DS kids stay happy and interested. A few have lost interest in doing anything...thus they became moody, unkept, show temper tentrums, unmanageable...which is very sad. Those were our early lockdown...but now we're better but it means for most we're back to zero...and start all over again. Such was our situation.

A year past...and we're 80% of what we were before the pandemic....such a relief.

Communication was our hardest to overcome....and not to mention disciplinary program. But fortunately we could slowly overcome it.

We added a few more programs to engage students to their daily activitist such as cooking and hip hop dancing. It seems to elevate their mood and make the whole household happy.

Hope we will lift the lockdown soon.

In meantime...stay safe and healthy everyone.
MONGOLIA

Since January 2021 Down Syndrome Association Mongolia has become a part of the Partnership Committee of General Authority for Development of Persons with Disabilities, Mongolia. This key government agency’s role is to implement policies and legislations on rights, social participation, development and protection for people with disabilities in Mongolia, to improve a quality of their lives providing the equal rights and participation in the social relations, and to educate PWDs to be independently developed. It is the first time a community for intellectually disabled (Down Syndrome) represents governmental committee in order to be a devoting value between stakeholders.

One of the accretive goals of DSAM in the rest of 2021 and up coming year is to help our young adults to get proper working and social skills in a supportive vocational environment. It will help our self- advocates build effective life, be successful and well prepared for social life and employment. Development of a component project for on-the-go Vocational Training Centre is in progress.

What changed for you during the pandemic?
What did you do to stay well?
Any thoughts you’d like to share with others?

<table>
<thead>
<tr>
<th>Name &amp; age of self-advocates</th>
<th>Answers to the questions</th>
<th>Attached</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bolor-Erdene, 28</td>
<td>What really CHANGED in my life? Diet. Video chats with my friends, dancing and experiencing different ways of cooking HELPED me to stay happy. What I’d like TO SHARE WITH OTHERS? The most important “thing” in this world is your family!</td>
<td><img src="image.jpg" alt="Image" /></td>
</tr>
<tr>
<td>Byambasuren, 24</td>
<td>Main CHANGE was managing everyday routines without being reminded. Lots of reading, talking to my parents, regular exercises and video chat with my friends HELPED me to stay well. Main understanding? Personal responsibility for your own health.</td>
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<tr>
<td>Erdenebold, 27</td>
<td>Main CHANGE in my life is wearing masks. I missed my friends awfully! Only video chat with my friends HELPED me to stay happy and less irritated. I started help my mum to do the housework, it was a real fun.</td>
<td></td>
</tr>
</tbody>
</table>
| Elberelt, 25 | Most unpleasant CHANGE was limited active movement.  
| | What is really HELPED was yoga and treadmill exercises with my mum every morning.  
| | Main understanding? Try your best to be able to protect yourself from the viruses |
| Ninjin, 26 | Main CHANGE was limited movement and lots of passive sitting.  
| | Music, dancing and video chat with my friends and relatives HELPED me to be happy.  
<p>| | My main understanding is a value of my peaceful home with my beloved family! |</p>
<table>
<thead>
<tr>
<th>Name</th>
<th>Description</th>
<th>Main change? I started working, so main change is lots of computing.</th>
<th>I was too busy with my job, so tried to help my mum with housework as much as I could. Main thought I’d like to share with others? Never forget how important is your family!</th>
</tr>
</thead>
<tbody>
<tr>
<td>Enkhbayar, 37</td>
<td>I’ve become the main helper of my mum. It’s a CHANGE number one. Dancing, listening my favorite musics and video chat with friends HELPED me a lot. Main understanding during the quarantine? How important masks and social distancing are!</td>
<td></td>
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</tr>
<tr>
<td>Temuulen, 20</td>
<td>A big CHANGE is boring time with no visits to anywhere. What HELPED me the most? My beloved mum and dad, video chats with my relatives and friends, great movies and music thanks to Youtube and Unite! My thoughts to share with others? Be a good person, especially during the hard times. There were lots of negative comments on Facebook.</td>
<td></td>
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<tr>
<td>Dulguun, 27</td>
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</tbody>
</table>
2021, the unexpected year of Myanmar. In 2020, Myanmar was faced with Covid-19 like other countries but we all were trying to overcome and be flexible with a new normal life. However, in February of 2021, the political transition of Myanmar turned down to dictatorship from democracy because of the Military coup. The strikes and demonstrations against authoritarianism are happening in the whole country.

The current situation is very bad and this is the difficult time for us. The people are hopeless and they are living with fear. No one can guarantee our living and there is no life insurance. That affects the citizens with cognitive disabilities and their families a lot.

On the other hand, the country's economy is getting worse and an economic crisis is happening in Myanmar. As the prices have increased
a lot and the parents are jobless and survival is the biggest effect on them. Although we all are facing such the difficult time, we still have things to do, especially the prevention of Covid-19 and the emergency support for our Down Syndrome People.

Firstly, we have to arrange the Supporting Program. We provided cash-for-meal and the rice packages for each member’s family during the Covid-19 pandemic, from the association’s fund and the Donors.

As part of the prevention from complications of the two diseases of seasonal flu and Covid-19, persons with Down syndrome were provided flu vaccinations in May 2021. Concerning with Covid positive case, there were only two persons with Down Syndrome who suffered Covid positive before the military coup. But we were able to support them both physically and mentally. As a result, those two people are getting healthy and overcoming from Covid. We also gave Psycho social support to many families including the persons with Down syndrome under the guideline of the Pandamar Covid group.

As our organization MDSA can do networking not only with disability organizations but also with diverse organizations, we can support not only information but also food, cash, prevention kits and etc. we always try to sort out the situation as much as we can. Whenever we get less or more funding or support, we always contribute to the community and support their families. On the other hand, MDSA is trying to create the Job opportunities for people with Down Syndrome. Our association initiates to produce the hand gel and hand spray which are made by our people with Down syndrome.

As we mentioned above, we are struggling and building the resilience to deal with the current’s situation. However, we need other countries’ support, donations and care for our people. In the country’s Rehabilitation Process, we need support and attention from international organizations. So, please help Myanmar by speaking out about our country’s situation. Please look carefully to our people with all of your sympathetic mind and empathetic hand. On behalf of Myanmar Down Syndrome people and the citizens, may I express our thankful heart to you all. May you all be safe and healthy.
PAKISTAN

PDSA is committed to rehabilitate Children with Down in Pakistan

- Abid Lashari

KARACHI: Pakistan Down Syndrome Association (PDSA) is engaged to provide free rehabilitation services at PDSA-NDF Rehabilitation Center in Nawabshah, Sindh Pakistan. The center caters needs of 100 children with Down Syndrome & other learning disabilities. The children are provided boarding and day care along with free pick & drop. The children are provided Psychotherapy, Speech Therapy, Occupational Therapy, Physiotherapy, non-formal Education & indoor/outdoor games. During COVID-19, PDSA engaged self-advocates & other children through home visits & online video calls. The purpose of online sessions to keep continue coordination with children to stay their learning live, if disconnected they may loss previous progress.

PDSA future plans are to keep continue in-person sessions, which started from 7th June, hope children will be engaged in lively activities to grow up towards mainstreaming. PDSA will replicate good practices of APDSF members in Pakistani children for their grooming.
More than a year has passed since ‘Our Lives, Our Voices’ (OLOV) pivoted to having weekly online sessions via Zoom. It hasn’t been an easy journey for many self-advocates as they grappled with learning to use the video software amongst a myriad of other changes during this pandemic. Nonetheless, the joy of seeing each other’s smiles (virtually) always lifts all our spirits and makes everything feel better!

Throughout the past year, the self-advocates continued to share their lives with one another and explored a variety of topics. Some of which, like learning to create and use our own email address, were aimed at embracing technology and other forms of communicating with one another.

One highlight during this period was witnessing the sense of ownership and creativity demonstrated by the self-advocates. Many volunteered to take on the role of Game ICs during sessions and went about planning fun activities for their peers. Several self-advocates also stepped up to deliver presentations to our partner organisations, preparing their scripts and PowerPoint slides. We were very encouraged by all their efforts and were in awe of the digital skills displayed!

OLOV has been blessed to journey with each self-advocate, and we will continue to walk with one another through the various seasons of our lives, pandemic or not!

Group picture from a lunchtime presentation by OLOV self-advocates to SG Enable
About ‘Our Lives, Our Voices’:
The first Self-Advocacy programme of its kind in Singapore established jointly by the Movement for the Intellectually Disabled of Singapore (MINDS) and the Down Syndrome Association (DSA) of Singapore. OLOV empowers and develops youth and young adults (age 16 and above) with intellectual & developmental disabilities to become self-advocates. The project seeks to do so by:

1. Supporting self-advocates to express their feelings
2. Empowering self-advocates to speak up for themselves
3. Educating self-advocates about their rights & how to be a responsible citizen
SRI LANKA

In Sri Lanka, the Covid-19 pandemic has completely paralyzed the activities of all the government institutions, private establishments, schools and general activities of non-governmental organizations. There is no improvement. With increased travel restrictions, and other related issues we are unable to plan any long-term projects now. Children are at home and the schools are still closed. All special schools are closed since last year. Teaching has moved onto online classes and there are multitude of issues in functioning distance learning in the country, especially in rural villages.

We are continuously keeping in touch with our member families. Children with DS are getting better attention from parents. That’s the only positive outcome of this situation for them. The country is progressing with the Covid-19 vaccination drive. Still it is being given to people above the age of 60 years. No special attention to children with Down syndrome which is a major issue – there are no established system to properly connect with this community island-wide.

Many parents are requesting us to establish a home for DC children. But we cannot run a home for DSC as our objective is to serve the DS children scattered in all corners of the island. Our main target is to form 100 or more DS. We have selected 52 locations to establish DS well fair clubs.

Actions planed for the future.  
- We have successfully signed the MOU with AIESES to bring down 10 foreign volunteers to work with us to strengthen the activities of welfare clubs within 6 weeks. The foreign volunteers would work with preschool and special schools and execute the following functions.  
  1. Helping kids with handicrafts, aesthetic activities, and other skills development activities  
  2. Help teachers and DS children to do gardening  
- Now we are in the process of requesting funds for this program from donor organizations.
The other plans for the 2021-2022 remain the same.
1. Main task is to form Down syndrome welfare clubs in many parts of the country.
2. Implement training programs for the preschool teachers in the island to give training to accommodate children with DS in their schools.
3. Counselling programs for parents
4. Organize awareness programs for school children.
5. Printing and distribution of medical record books and diet chart books.

But all depends on the Covid-19 pandemic situation in the country. At the movement it is impossible to do any program except contacting the parents of our member families in order to keep hope for the people with DS and their parents.
We are delighted to announce the new dates for WDSC 2021 that will be held virtually between 18-20 November 2021.

Our main priority is the safety and well-being of our participants, and by moving the virtually, we aim to protect our delegates from any potential health risks, as well as avoid travel restrictions that already placed on many countries and would limit the ability of some delegates from attending the congress.

Despite the postponement, the preparations for the congress have continued without interruption and the WDSC organizing committee remains committed to keep this congress into an enriching and incredible experience for all.

More information along with the virtual platform of WDSC Dubai 2021 will be announced soon, please feel free to contact us for any inquiries on info@wdsc2021.org

We are looking forward to welcoming you to the World Down Syndrome Congress Dubai 2021.