



ASIA PACIFIC
DOWN SYNDROME
FEDERATION



APDSF E-News

APDSF Newsletter

January - March 2022

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PRESIDENT SPEAK



Hello Members.

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

Thank you for responding to our request for articles for the year's first edition of the newsletter.

2021 has been another year of lockdowns and pandemic related issues. We have had to face hardships; however, we have also emerged stronger. All the initiatives taken by our members to support our dear ones with Down syndrome have made us feel proud with their achievements. Our self-advocates have been phenomenal – continuing their habit of wearing masks, social distancing and staying at home. They have also become adept at handling the online space and seem to have bettered us in this domain too.

As the saying goes, "Tomorrow is another day". I hope 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.

Stay healthy, Stay safe.

N. Ramachandran
President
Asia Pacific Down Syndrome Federation

Down Syndrome Society of Bangladesh is a platform for children born with Down syndrome and their parents. The sole purpose of this platform is to inspire children born with Down syndrome by enabling them to help change the world and assist them in special needs advocacy, education, employment and social inclusion.

As a non-profit organization, we work closely with health and educational professionals and other voluntary welfare organizations. The Society is affiliated to national and international bodies such as the Department of Communication Disorders, University of Dhaka, Down Syndrome International (DSI), Asia Pacific Down syndrome Federation and regularly works in



collaboration with other Down syndrome organizations worldwide.

1. Celebration of Down syndrome Awareness Month

- **Deep Down Art Bangladesh Competition**

On the occasion of the 6th year celebration of World Down syndrome Awareness Month October - 2021,

Down Syndrome Society of Bangladesh has organized Deep Down Art Competition - Bangladesh for Children and Adults with Down syndrome. This is a great opportunity for the children and adults with Down syndrome to demonstrate their skills and talents in our community.

Video:

<https://www.facebook.com/DSSocietyBangladesh/videos/589343335519260>

▪ **Participation in Paul Down syndrome Award Competition**

S Rafan Razzak won 4th prize in category Art and received his award. Here is the Channel i news...Cheers!!

<https://www.facebook.com/DSSocietyBangladesh/videos/894625201422966>

2. Inclusion Works – Including Persons with Down syndrome and Intellectual Disabilities in Employment.



- **Employment Advocacy Activities :** <https://youtu.be/aElhIxf7T5g>
<https://youtu.be/pFGkcwZq7dc> <https://youtu.be/clghASemfZs>

Achievements:

- During the COVID-19 situations across the country persons with Down syndrome and intellectual disabilities were able to learn how to protect them.
- Self-advocates, Parents/support persons/caregivers motivated and sensitized on right to employment.
- Self-advocates capacities were enhanced through advocacy activities and on the job training
- Nearly 15 selected employers reached through employment advocacy activities.

- Commitment achieved from few companies for possible internship program and scope of on-the-job placement after the COVID-19 pandemic.



3. Self-Advocacy Meeting - Inclusion Work Project

Under the Inclusion Work Project, supported by Inclusion International, DSSB has been conducting self-advocacy meetings to promote inclusive employment in formal job sectors.

Achievements:

- Self-advocates raised their voices for employment.
- Self-advocates demonstrated their skills for employment.
- Employers shared the available opportunities in their companies for employment.
- Selected employers sensitized and oriented regarding employment for persons with Down syndrome and intellectual disabilities.
- Some companies like Japan Bangladesh Friendship Hospital and others confirmed and committed to recruit a couple of self-advocates in the near future after the pandemic is over in the country.
- Local governments of Dhaka, Gazaria, Munshiganj assured to provide their support and cooperation for the employment of adults in the areas.

<https://youtu.be/SL5xhPMoKKs>

<https://youtu.be/6qCF0VD87xg>

News of JBFH : <https://bit.ly/3tCH7IM>

<https://bit.ly/31a0AEI>

<https://bit.ly/328s7qS>





▪ OPD Monthly Coordination Meeting (ADD)

Under the Inclusion Work Project we have regular OPD meetings with ADD International Bangladesh. Keeping social distance we have organized those meetings with limited participants.

4. Inclusive Dream Project

An amazing initiative...
 With the vision of a future Bangladesh that will be Inclusive, JCI Dhaka West collaborated with mainstream Schools of Dhaka to arrange a virtual Writing competition followed by a session on Down syndrome. We believe children are the future and they need to be better than us for a better world. For a Bangladesh without discrimination against any form or disability this small initiative will be the bridge between mainstream and people with Down syndrome and other form of neuro developmental disabilities.

INCLUSIVE DREAM PROJECT
 Initiative Towards an Inclusive Bangladesh
Episode 1: Stories of Down syndrome
 JULY 3, 2021
 11AM-12.30PM
 EXCLUSIVE FOR BAF SEMC

SARDER ABDUR RAZZAK
 Key Speaker
 Chairman
 Down Syndrome Society of Bangladesh

KHAYAM SANU SANDHI
 Guest Appearance
 Singer, songwriter

KAZI FARHANA
 Program Presenter
 Local Treasurer, 2021
 JCI Dhaka West

JCI Dhaka West | DSSB Dhaka West

The younger generation is unaware of such conditions in human beings due to the lack of education on this. As a result, we see less and less inclusion of people with disabilities in the workplace and society in the youth. This event will be the beginning of a journey towards equal opportunity in our country. It is the people and the mindset we need to change and we are starting from the root. We welcome any willing and related stakeholders to be part of this change making towards a positive Bangladesh.

▪ Celebration of IDPD 2021 (International Day of Persons with Disability)

On 3rd December, DSSB celebrated International Day of Person with Disabilities

Photo:

<https://www.facebook.com/DSSocietyBangladesh/photos/pcb.3027817427463046/3027817210796401/>

Video:

<https://www.facebook.com/DSSocietyBangladesh/videos/608739943697675>

News: <https://bit.ly/3qMfT0R>

<https://bit.ly/33rd7VL>



- **Consultation on Global Disability Summit organized by National OPD Advisory Committee (NOAC)**

DSSB actively participated in the national consultation workshop on Global Disability Summit as an member organization of NOAC

Photo:

<https://www.facebook.com/DSSocietyBangladesh/photos/pcb.3028999330678189/3028999190678203/>

NEWS : <https://bit.ly/3rrycaG>

<https://bit.ly/3fBhRus>



- **Celebration of National Victory Day 16th December 2021**

DSSB Celebrates National Victory Day



Video:

Art competition : <https://www.youtube.com/watch?v=HT1nxJzeoHs>

Cultural Program :

<https://www.facebook.com/DSSocietyBangladesh/videos/29928463541592>

CHINA

Xiao Feng's Story

Xiao Feng is a 14-year-old boy who lives in Shanghai and studies in an ordinary middle school. Although he is a boy with DS, he is among the best in his English class.

When he was 11 years old, we met in the self advocacy experimental group. His performance was impressive.

He told us that he would never forget his great grandfather's last words: "We are not afraid of any difficulties!"

WE ARE NOT AFRAID OF ANY DIFFICULTIES.

This has become a motto for us ever since.

Xiao Feng is a born leader. Once we planned to play music together with wind chimes, singing bowls, wave drums and other musical instruments. He took the initiative and he asked everyone to ring their instruments one by one. Listening carefully, he directed us to play in the order he specified. He is a natural conduct of music.

This made me realize the importance of self advocacy.

One day he hopes to meet you at WDSC.

Hello, Tangbaobao in the Asia Pacific region. My name is Tangyiteng. I'm thirteen years old this year. I come from beautiful Shang China. I am a kind, brave, clever, honest and helpful person. There are six people in my family such as my mother, my father, my grandmother, my madame and my grandpa. I have a lot of interests such as reading, travelling, painting, listening to music and photography. I have four good respect such as do homework regularly, help family do housework, study hard and good at painting. I have only one bad respect that's I can't told my quilt. I enjoy life and nature, I hope every Tangbaobao like life and nature too. Let's cheer together.

Xiaofeng's handwritten letter to APDSF

(Tangbaobao is a nickname for Down syndrome kids in China)



First met in the self advocacy experimental group, February 2019



Recent life photos of Xiaofeng

INDIA

The year 2021 was a watershed year for all of us. India was no exception. While 2020 was a year where we understood the importance of social media during a time when we were not able to meet, 2021 took the usage to another level. The online space became our outlet and self-advocates became more adept at handling it.

What were the activities conducted by the Federation this year?

1. Online sessions for parents:

We had many online sessions specially for parents. Experts from the field of medicine, therapy, education and motivation were there to speak to our parents and answer their queries and clarify doubts.



2. Story Telling for self-advocates

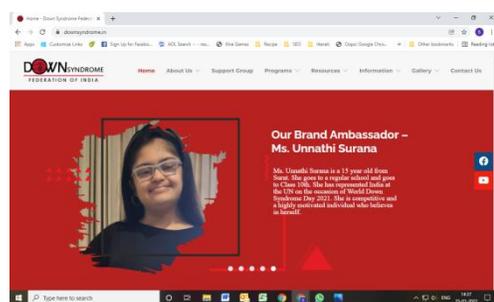
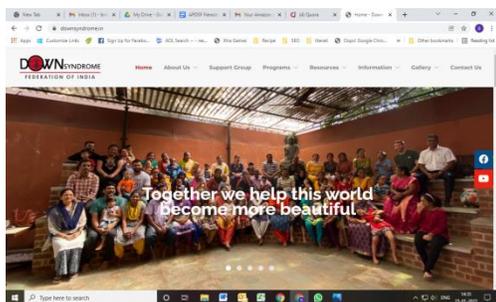
Our story telling session was one of the biggest hits for us. Self-advocates across the country joined us for these sessions and how they enjoyed it. Shivani, our story teller asked them questions, riddles and even quizzed them on their knowledge to make it an interactive fun session.



We asked our parents to send us a picture of their self-advocate that shows the love of a family. And we got so many heart-warming pictures, we felt humbled.

3. Website revamp

The Down syndrome Federation has revamped their Website to make more appealing and easier to navigate. We continued with the Red theme of the Federation. Kindly visit our website www.downsyndrome.in



4. Online Medical Camps

We organized online medical camps for persons with Down syndrome across the country. These camps were well attended and we had to restrict the number of attendees due to the session being online. However, the doctors and therapists were very co-operative and we managed to meet a lot more parents than we thought possible.

5. The India International Down Syndrome Conference (IIDSC 2021)

IIDSC is an annual affair and we had gone online in 2020 due to the pandemic. This year too, we had to organize it online. We invited the medical fraternity and therapists to address our parents and caregivers. We got more than 300 attendees for the event online. With more joining in over the live Facebook telecast. Our Self-advocates also performed during the event as we usually do offline. In 2022, we hope we can do it offline, since we realize that it is important for parents to speak to them directly.



6. Online Course for Down syndrome

DSFI had in the year 2019 started the First of its kind online certification program in association with a training centre that had the approval of the Government of India. This course has seen a minimum of 40 candidates per course. The 3rd batch of students gave their final exams at the beginning of 2022. Out of the 45 students, 28 of them passed the exams this year.

This course helps parents caregivers and medical and health specialists to go in-depth into Down syndrome, understand it better, understand the self-advocates better and is one of the steps taken by DSFI to create an inclusive society.

7. Foreign Contribution can be accepted by Down Syndrome Association of Tamilnadu (DSAT).

One of the affiliates of DSFI, the Down Syndrome Association of Tamilnadu can now accept Foreign Contribution from donors abroad. Recently, DSAT was given the permission from the Ministry of Home Affairs, Government of India to receive funds from individuals/organizations who would like to support the cause of Down syndrome in India.

8. Support for Surgery and other medical issues

We have been supporting persons with Down syndrome for their financial needs during surgery and other medical emergencies. This year too, we supported many children whose parents could not afford the high medical costs.



DSFI continues on its journey to make life easier for persons with Down syndrome in the country.

INDONESIA

Greetings from Indonesia.

We hope that everybody is doing well during this pandemic and uncertain situation. For the beginning of this year, still the same as last year, POTADS INDONESIA still focused on online activities and classes.

Some of our events in 2021 are:

1. Down syndrome Got Talent : #downsyndromegottalent
2. At Home Stimulation activities for kids with down syndrome: #lombastimulasipotads
3. Virtual Drawing Contest for Down syndrome Kids : <https://youtu.be/MSmdpxZf9wM>
4. Series of events celebrating Down syndrome awareness month :
 - a. Zumba : [https://www.instagram.com/tv/CUjIwU leY8/?utm_medium=copy link](https://www.instagram.com/tv/CUjIwU leY8/?utm_medium=copy_link)
 - b. Webinar :
<https://youtu.be/keA5RX4rOIw>
<https://youtu.be/Nmx08n3NC2E>
 - c. Down syndrome and Friends in Virtual Harmony : <https://youtu.be/MVe-rjzzAb4>

As we know that pandemic may also affect the social emotions of kids with Down syndrome due to their very limited activities during this coronavirus outbreak, so on 22nd January 2022, POTADS held a webinar discussing this issue with a professional psychologist as a speaker.

100 participants joined this event via Zoom Meeting and many others were attending through our youtube channel :

<https://youtu.be/x1a VI5qEKU>



We also have also planned a series of events for 2022 and we are looking forward to celebrating World Down Syndrome Day 2022. We do hope that in March we can celebrate it with an offline event.

Some of our plans for World Down Syndrome Day 2022 are Down syndrome got talent Season 2, At Home stimulation video contest, free medical examinations for down syndrome kids, charity bazaar and POTADS Carnaval.

To connect with POTADS Indonesia please visit our social media:

www.potads.or.id

www.instagram.com/potads/

<https://youtube.com/channel/UCG9834LqYqkKuYS7qgiE2qQ>



MYANMAR

Myanmar Down Syndrome Association would like to wish you all a happy new year in 2022. 2021 to 2022 has been a long journey.

We had to pass the whole year with many challenges but we stand with our never-say-die spirit for our Down syndrome community. Because of that spirit, we were able to perform a lot of activities with the cooperation and collaboration of our Myanmar Disability network.

No.	Activities from 2021 July to 2022 January
1.	Covid Prevention Activity
2.	Physical support for resilience in daily living
3.	Mental support for emotional wellbeing
4.	Educational Support for sustainable learning
5.	Development & Empowerment Program

Covid Prevention Activity

Covid Crisis is the biggest issue in the whole world. As a struggling country, Myanmar people have to support each other. Our

people help and solve problems together. MDSA conducted the distribution of the Covid prevention kits with the cooperation of other disability organizations. With the support of some donors, we were able to provide the Covid Vaccine not only for the EC but also for

the member people with Down syndrome who are above



18 years old. In addition, we were able to provide the seasonal flu vaccine with the organization's Fund.

Physical support for resilience in daily living



During the crisis, it is really difficult to survive even for a meal during the day. With the aim of providing physical wellbeing, and the objectives for shaping the attitude of our community for eating the meal with the low price but with the full nutrition for the body, our MDSA is donating the nutritious meals by cooking with the healthy way for the children, teenager girl, the pregnant women, elder persons and people with disability. By performing this activity, we can bring the local society to creating a warm and helping environment, enhancing the participation of persons with Down syndrome, and building resilience for the current situation.

Moreover, we are supplying the CASH for basic needs with the cooperation of donor organizations.

Mental support for emotional wellbeing



To build the never-say-die spirit, we need to cure our mind. Thus, MDSA is enhancing the mental support programs. We connect with other organizations and provide FOC programs for the Yoga Club and conduct the emotional wellbeing workshops for Down syndrome families.

Educational Support for sustainable learning



When we talk about development, we can't skip the educational development. Because of the crisis, the education programs

are delayed. To fill that gap and to provide sustainable learning for students with intellectual disabilities who are difficult for the schooling, we are planning to initiate home based learning programs by using the Home based learning kits from Save the children.

Development & Empowerment Program

By empowering Intellectual disability families with the support of household small businesses, we believe that we can build resilience for them and we can raise the funding or self-income of disability people while they are reducing their expenses by

using their handmade liquid sap. Furthermore, we can change the attitude of the community on the capability of disability people. Therefore, MDSA arranges to produce the homemade liquid soap with their capacity by providing the raw materials.



At the same time, we promote the role and inclusion of people with down syndrome by creating “My Role Video and Photos Competition” as the **Down syndrome October Awareness Month Program** . From that competition, we can learn more about the daily life of PWDs, their points of view and their capacities.

Those become the prioritized facts in planning the future activities of MDSA.

Meanwhile, MDSA is extending the networks with other organizations, and enhancing the capacity of EC members by arranging empowerment programs, trainings and discussions.

Conclusion

To sum up, everybody will have difficulties and challenges. But we have to be aware that we can overcome those by building our never-say-die spirit. For that spirit, we need to be hand in hand. We wish you all to be stronger by keeping our never-say-die spirit for the fruitful years of 2022.

MONGOLIA

Government policy



Down Syndrome Association Mongolia was invited by the Prime Minister of Mongolia to be an official member of the 'National Council for Children.'. Also started cooperation with the National Police Agency to draft regulation and guidebook for all armed forces of Mongolia on how to communicate with people with Down syndrome. And working on the revision of the Disability Rights Law Mongolia.



International Day of Persons with Disabilities

On the occasion of the Day for the Protection of the Rights of Persons with Disabilities, the Mongolian Down syndrome Association held practical discussions with its partners on issues related to the

employment of people with Down syndrome and shared their experiences. This discussion will focus on how the government, the private sector, and NGOs need to work together to provide jobs for adults with Down syndrome, how to train interns, and how to work with developed countries and international organizations to learn from international best practices. They exchanged views on how to work and talked about how to implement many ideas and initiatives in 2022. It is the first place in Mongolia to hire people with Down's syndrome and still provides them with stable jobs in Shangri-La Ulaanbaatar. GCR Mongolia is a model organization that provides jobs for young people with the most Down's syndrome. The Asia Foundation Mongolia is the first organization in Mongolia to promise lifelong employment for people with Down syndrome.

Entertainment

“The Wasabies” Mongolian famous girl band has been selected as an ambassador of Down Syndrome Association Mongolia. They are wanted to show to the public that children with

disabilities are a component of society like us. Therefore, Band members and DSAM created four serial comic books for children.

The Down Syndrome Association has



movie production

An actor with Down syndrome inspires and stars in Mongolian films which will be nominated in international film festivals. It is the first-ever Mongolian film to feature an actor 10 years old boy with Down syndrome in a lead



worked on two movie projects.

- Name of movie TRIO, it made by domestic



role.

- Name of movie Stairs, it made by Bus Stop film (short Story movie) Bus Stop Films promote inclusive education in Mongolia through filmmaking and storytelling, as well as teaching social, work-ready, language, and literacy skills to students with and without disabilities at the Media and Arts School in Mongolia. Bus Stop Films in Mongolia was a 12-month program, in partnership with the Arts Council of Mongolia. With local creatives, the program established an Australian-made, Accessible Film Studies curriculum in Ulaanbaatar. The program was designed to provide filmmaking workshops for people with intellectual disabilities to increase their literacy, communication, job readiness, and confidence.

Sport

The Mongolian Football Federation (MFF) brought joy to two children with Down syndrome during the Mongolian Premier League. The two children will forever cherish the moment of marching together with the players into the stadium and being allowed to score a goal before the match properly started. Both children were ushered off the pitch as players applauded their efforts. This news has been posted on the Asian Football Confederation website officially!



Online training and workshop

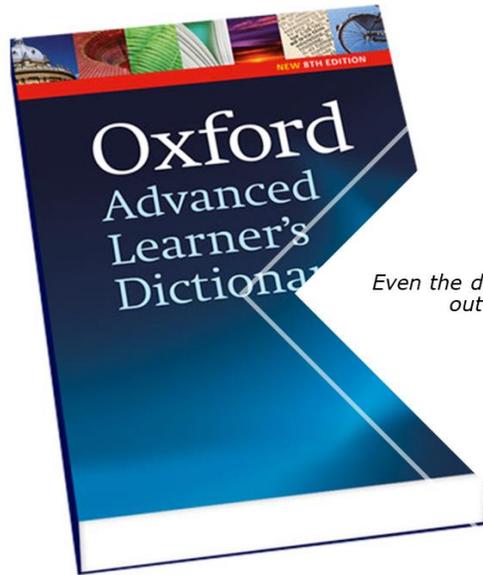


During the pandemic, we published and delivered over 10,000 guidebooks and produced a series of online training for parents, reference set packages for doctors, nurses, teachers, and social workers all around the nation in cooperation with JICA, people from Japan.

International campaign

“Mongol Identity” NGO launched a campaign for improved dictionary definitions of the word ‘Mongol’ to help counter racism and discrimination against people with disabilities.

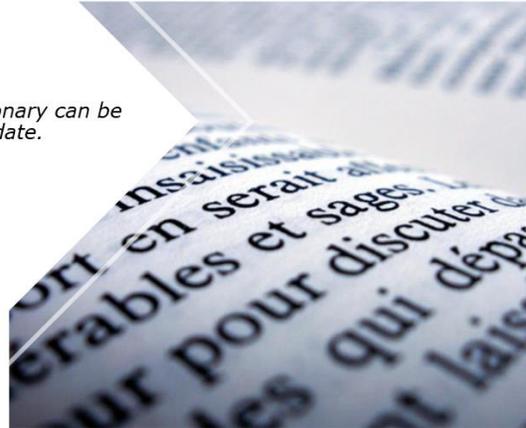
We approached the Oxford Advanced Learner's Dictionary and are very pleased with the outcome.



Even the dictionary can be out of date.

Our campaign for improved dictionary definitions of the word 'Mongol'

- 23, 2021



NEPAL

Make the world believe in your strength, nobody knows what is to happen the next moment. It is all about how much strength and positivity you have to fight the upcoming obstacles in life. · My name is Radha Khatri and I have two children. We have a 19 year old daughter and after a long gap, having focused on building our careers, we planned for our second child. Three years ago our son, Rasik was born and he has Down syndrome.

After two months of Rasik's birth, he was hospitalized and in critical condition for nearly four months. He was put on a ventilator and while doctors lost hope, I stood strong to see him smile and take him home in healthy condition. During the second lockdown when times were dreadful, I Googled and found Dr Lalita Joshi's number. I called her and she was so receptive, consoled us and gave the best advice for care and support of my son and family as well.

My son is healthy and active, progressing well slowly and steadily .All the credit goes to this wonderful simple lady.

We met Dr Joshi for the first time in November 2021 in person. Without knowing us, she was so helpful. We are truly impressed with her spirit to help the needy.



PHILIPPINES

Greetings to all!

The Down Syndrome Association of the Phils, Inc (DSAPI) is looking forward to a milestone celebration in 2022 as it marks its 30th year! February is the National Down Syndrome Consciousness Month in the Philippines, and with over 26,000 members in its Facebook page, DSAPI has lined-up several activities while avoiding in-person events to ensure everyone's safety and good health.

February 1: It's about time for DSAPI to have its very own song, and everyone can eagerly await the launching of "Natatanging Nilalang" which translates to "Unique Being," which was lovingly composed by Ronnie Lee who is very fond of his nephew, Jeremy Lapena, 25 years old, with Down syndrome.

February 6 marks the foundation day of DSAPI. Who would have imagined how this community would have grown after 30 years? From a handful of eight parents and two doctors, it is amazing to have developed into an organization that has spread throughout the country. Look out for messages on the DSAPI Facebook page from the founding members, officers, parents, sponsors, partner organizations, government institutions and all other strong supporters that have made DSAPI flourish through the years.

February 14 may be Valentine's Day for most but for DSAPI, it also marks a special celebration. It's not a coincidence that the logo of DSAPI is a heart with a child. As the Chairman Emeritus and founding member Antonio Pasia recalls the very words from Dr. Jerome Lejeune to parents during a visit to Manila on November 27, 1992, "Love the child as a child first, and the child will bloom."

February 27 shall be the culminating activity for the month-long celebration with no less than the main event that everyone can look forward to which is the Happy Walk with this year's theme, "Sama-sama All For Down, 30 Years na Tayo!" which translates roughly to "Together for Down, We are 30 years now."

And finally, for all avid golfers, all are welcome to join the 20th Tee-up For Down Golf Tournament which can be played at any course. Donations are welcome to be counted in the lucky draw at the end of the month.

All these activities shall make the 30th year celebration more memorable to all. Congratulations DSAPI! May you continue to grow long into the future!



SRI LANKA

BILATERAL ADRENAL TERATOMAS IN A CHILD WITH DOWN SYNDROME

Dr.K.G.Dayaratne (MBBS), MD(Radiology),

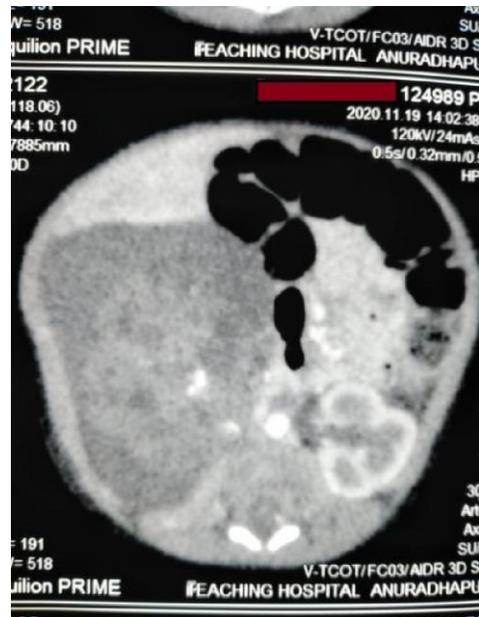
Consultant Radiologist, Teaching Hospital Anuradhapura, Sri Lanka

It was another day for the department of Radiology, Teaching hospital Anuradhapura, in November 2020. I was the consultant Radiologist, appointed for ultrasound scanning services for the particular day. There was a request for an urgent scan from a consultant neonatologist for a newborn girl with suspected abdominal mass. The baby has shown the clinical features of Down syndrome as well. Ultrasound scan of the abdomen revealed a large mass lesion in the either side of the abdomen.

My memories went all the way back to 2014, when my son was born with the clinical features of Down syndrome. I could easily understand the mental stress and curiosity of the parents with regards to the immediate and long term outcome of the child. We had a multidisciplinary team discussion regarding the further management of the child with the participation of consultant neonatologist, pediatric surgeon, radiologist and oncologist. Meanwhile genetic study confirmed the diagnosis of Down syndrome.



We arranged an urgent CT scan of the abdomen for the confirmation of condition and pre-operative assessment. CT scan features were compatible with bilateral adrenal teratomas.



CT scan images showing bilateral adrenal tumours

There was a team discussion with parents regarding the diagnosis, management and possible outcome of surgery. In addition, neonatologists have had several sessions of counseling for the parents. Surgical team optimizes the child a few months prior to surgery allowing for adequate weight gain.

This family is from a village known as Rathmalgahawewa, which is 30 km away from Anuradhapura. The father of the child is a farmer and mother is a housewife. There is a 12-year-old healthy elder sister in the family.

Bilateral adrenal tumour resection was done by the surgical team led by consultant pediatric surgeon. The child had uncomplicated recovery following postoperative ICU care. Histological assessment confirmed the adrenal teratomas, and the child was referred to the oncologist for further management. At present, the child is one year old and performing reasonably well in growth and development. .



This scenario showed the dedicated service of Teaching hospital Anuradhapura for a child with Down syndrome even during covid pandemic. I could give the best out of the way as a radiologist in initial diagnosis and follow up care. I shared my knowledge and experience as a father, doctor and an active member of the Asia Pacific Down Syndrome Federation. Most importantly, I had a golden opportunity to give mental strength to the family in addition to financial support.

OUR PRECIOUS BABY GIRL JINENDHI

We were blessed to have a baby girl at a time when we had almost given up having another child, a precious gift to look after and keep her happy – She is Jinendhi!

We had three sons of ages 14, 12, and 08 when both my husband and I were in our early 40s.

We never thought it was too late to have a daughter and we considered ourselves lucky to have a girl in the family. The three sons were happy to have a sister which was a great welcome. After bringing up 3 healthy sons, I did not need much assistance in caring for a newborn, but I did notice many differences in her movements and suspected, her to be baby with Down syndrome.

I was a high school Biology teacher and had taught my students multiple times about Down syndrome and the characters of such a baby, in the genetics lessons. Our daughter had a flat nasal bridge and slanted eyes.

The pediatrician confirmed our suspicion. I was really depressed even though my husband didn't take the news as that bad.

When I asked the doctor about what will become of her, she said it all depends on how you bring her up; she might be a better human, than your so called normal and healthy three sons. I made up my mind to train her to be happy and a useful human.

The three brothers and Jinendhi 's father were very cooperative in bringing her up. At the age of 4 1/2 yrs. she was admitted to a government special school where the teachers were very kind and tactful. She gradually learned to read, write and behave well in society.

When Jinendhi was about 21 years old, we faced a tragic situation. Our three sons got married within one and a half years, the 2nd and 3rd sons went abroad for higher education with their wives. The elder son had a new son born to the family and we were really excited with the 1st grandchild at home. Meanwhile, Jinendhi would have felt neglected which we didn't notice much, but she gradually stopped talking and was restricted to a corner. How much we tried to talk to her was of no use. With our son's advice we took her to a psychiatrist who diagnosed the condition as a mild state of depression more common in children with DS, which we didn't know. Luckily, she got back to normal after treatments.

Jinendhi is 29 years old now. All her brothers are married and have families of their own. Jinendhi lives with us at home and accompanies us wherever we go. We never feel lonely at our age as our beloved daughter is around us. She likes sewing, as that's my hobby. · I trained her to stitch rags out of gunny bags, make table mats and she also helps me with

gardening which is another favorite of mine. She gets up early in the morning and goes for a walk with me and neighbors. She gets on with neighbors very well. She has never been an agony to any one of us. She loves to play with her nephew and nieces.

She had many opportunities to travel to the USA and Australia, as one of my sons live in Australia and another one in USA. She has traveled to countries like India, Singapore and Myanmar.

My husband had a vision to serve the other deserving children with Down syndrome in Sri Lanka. As such, in 1996 he founded the Jinendhi Resource Centre for Down syndrome (JRSFDS) in Sri Lanka, to serve these deserving children.

We have exposed her to almost all the events and gatherings. The theme of the JRCFDS is to build a caring community for Down syndrome.

She is our treasure! It is a hard journey, but I found many reasons to be positive and raise her to become the wonderful person she is now. I am happy that I'm finding ways to counsel and support the mothers of newly born children with DS with my 30 years of experience in bringing up our daughter Jinendhi Galgamuwa.

Following are some pictures of Jinendhi actively interacting with various segments of the society and engaging in different activities throughout the day.



