

Report for Down syndrome Federation of India

The year 2022 has been a busy year for the Federation. The activities that took place this year are as follows:

- 1. The World Down Syndrome Day** was celebrated across the country. Various activities were carried out including cultural shows, lighting up of buildings and monuments in Down syndrome colors of yellow and blue, marathons where persons with Down syndrome went along with their parents and siblings, art exhibitions and many more. The best thing about this year was the enthusiasm. It was probably the fact that we are meeting up after the 2 years of COVID and this mattered to our self-advocates and their parents. In short the WDSD celebrations this year were one of the most actively participated ones across the country. Even cities like Lucknow, Madurai and Kolkata were at their festive best.
- 2. Representation at the UN in Geneva** – India celebrated the World Down Syndrome Day at the UN at Geneva albeit virtually. The session was attended by Mr. T. R. Narayanaswamy who provided the sibling perspective to the audience and how siblings need to support one another. The Indian Ambassador to the Permanent Mission in the UN, Mr. Indra Mani Pandey was one of the Chief Guests at the meeting.
- 3. Camps across the country** – Medical and Health camps were organized virtually as well as in person where various medical experts and therapists provided guidance to parents of children with Down syndrome. The camp at Lucknow which was organized in association with the Sanjay Gandhi Postgraduate Institute of Medical Sciences was well attended where the team from Chennai as well as the local medical teams was a part. The various issues of persons with Down syndrome were discussed and addressed. These camps are now being requested across the country since they are very useful for the parents in grooming their children
- 4. Assistance for Persons with Down syndrome** – The Federation sought donations for persons with Down syndrome who required surgery due to complications. Various donors came forward to assist children with Down syndrome. 11 Children were provided with help this year. Many parents come to us with a hope that we could provide the necessary assistance for various complications in their children. We have tried to help as many children/adults with Down syndrome as possible.
- 5. IIDSC 2022** – The annual conference organized by DSFI – the India International Down Syndrome Conference (IIDSC) was held in Raipur, Chhattisgarh this year from Sep 15-18. It was attended by almost 400 delegates including nearly 100 self-advocates (persons with Down syndrome). Expert Speakers in the area of Down syndrome from various parts of the country and world spoke on issues that need to be addressed and how. It was a very informative session with parents taking back

lots of inputs as well as memories from the conference. There was a session by self-advocates who spoke about their aspirations and achievements. This gave parents of younger children with Down syndrome more hope for the future of their child.

6. **Course on Down syndrome** - DSFI in association with various institutions is conducting a course on Down syndrome for the past 2 years. This year too the course was offered and Parents, Therapists, Doctors have joined this course which covers the various aspects of Down syndrome which a person needs to know to enable the empowerment of persons with Down syndrome. This course is being organized in collaboration with IRC, an RCI affiliated organization from Bangalore and Happiness is Khushi, an organization run by a parent. We are looking at starting courses on Special Education to enable Self-advocates to get ready for School.
7. **Zoom sessions** These Zoom sessions that we started during the COVID times to keep our community connected was so well-received that we decided to continue in spite of the opening up of schools and centers. We covered various topics that including medical as well as non-medical ones. To retain interest, we had various specialists talk about how persons with Down syndrome were affected in their area of specialization. Topics like stress, education and day to day living were handled by experts in these domains.
8. **Story Telling:** DSFI continued the Story Telling Sessions due to high demand for this session. The experts use various props available at home to involve everyone in their sessions. Our participants eagerly await the session. Parents say that the session has had a positive impact on the children and they are able to relate to the stories as well as the expert telling the story. They are more participative and are eager to expand and showcase their knowledge.

We are looking at supporting families of persons with Down syndrome across the country and hope to bring smile and cheer to them in the days to come.