ABOUT DOWN SYNDROME AND ACTIVITIES OF THE FEDERATION

About Down Syndrome

Down syndrome is the most common chromosomal condition in the world. It occurs in approximately 1 in every 800 live births. There are almost 40000 people born with Down syndrome in India. It is not related to race, nationality, religion, or socio-economic status. Nothing that a parent did or did not do during the pregnancy causes a baby to have Down syndrome. While the age of the mother can be a factor, 80% of people with Down syndrome are born to parents under the age of 35, simply because women in that age group have the most babies. Down syndrome occurs equally amongst male or female babies. People with Down syndrome, like any other person carry more traits of their birth family than the traits of Down syndrome. A person who has Down syndrome cannot be referred to as a “Downs kid” or a “Down syndrome person.” He or she is “a person with Down syndrome.”

Down syndrome is named after Dr. John Langdon Down, an English physician who first described the characteristic features of Down syndrome in 1866. “Down syndrome” is used, as opposed to “Down’s Syndrome”, because it was named after Dr. Down. When a person is born with Down syndrome, their cell development, results in 47 instead of the usual 46 chromosomes in each cell. Down syndrome also known as Trisomy 21, which describes the presence of all or part of an extra 21st chromosome. This extra genetic material causes changes in the orderly development of the body and brain, as well as the physical characteristics and delayed physical, intellectual, and language development associated with Down syndrome.

People with Down syndrome are more like their typically-developing peers than they are different. There is great diversity within the population in terms of personality, intelligence, appearance, humor, learning styles, compassion, compliance and attitude. Although they may share characteristics and similarities in appearance, children with Down syndrome will look more like their family members than they do one another. They will have a full range of emotions and attitudes, are creative and imaginative in play, and grow up to live independent lives with varying degrees of support and accommodations. People with Down syndrome benefit from loving homes, early interventions, special education, appropriate medical care and positive public attitudes. As with all children, quality education in neighborhood schools, preschools, and at home is important to provide the opportunities needed to develop strong academic and social skills.

About the Down Syndrome Federation of India

“Down Syndrome Federation of India” (DSFI) is an organization that offers support to individuals with Down’s Syndrome and their families through various Down’s Syndrome Institutions across India. DSFI is registered with the Office of the State Commissioner for the Differently Abled, Government of Tamil Nadu under Section 52 of the Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act, 1995.

Established in the year 1984, with 6 children, DSFI today serves innumerable children not only around India, but also the Middle East. Dr. Surekha Ramachandran's brainchild, DSFI has been a constant source of support and encouragement for people who are unable to come to terms with Down syndrome. DSFI has been working for the cause of all those who are affected by Down syndrome – whether it is individuals with Down syndrome, parents or siblings. Among the services offered include counseling distraught families, training children to overcome their shortcomings, providing physiotherapy, and speech therapy, and spreading awareness about Down syndrome.

Down Syndrome Association of Tamilnadu (DSAT) has been a forerunner in bringing about thought transformation for people associated with Down syndrome. The various therapies –occupational, behavioral, vocational, speech and physio has brought about a remarkable transformation in individuals who now seem more confident. Lot of research programs, awareness and outreach programs, specialized out-patient services, and early intervention programs are also conducted and co-ordinated.

Our Activities

1. Counselling

The primary aim of DSFI is to support families and persons with Down syndrome. Most of the time parents of persons wiht Down syndrome are not only disillusioned but also at crossroads not knowing how to handle their lives. They come to the center where the counselers and therapists help parents understand the problem of their children and provide a solution that would help them

Counselling is provided not only for parents of persons with Down syndrome, but also for couples who have been told that their child could be a person with Down syndrome. They are sent to the Federation by doctors who have diagnosed that they could have Down syndrome babies. These distraught parents are then counselled at the center and told about the various pros and cons of having children with special needs.

2. Early Intervention

The most important thing that parents need to know is the importance of Early intervention, The earlier the child is brought to the center for its therapies, the better the growth and development of the child. At the DSFI center, early intervention is carried out by experienced therapists and professionals who guide the children through various techniques in order to strengthen their muscles and also to guide them through the mental processes that will help them in the future.

Early intervention is essential in order to help Persons with Down syndrome to lead near normal lives. As they grow older, they tend to become more rigid and hence difficult to manage. Since parents would be keen to see their children growing up like their typical peers, it is essential to undertake early intervention.

3. Health Camps

DSFI organizes health camps all across the country in order to assist persons with Down syndrome an their families. Most of the times parents are not sure about the various therapies or health issues associated with their children. During these health camps, therapists, special educators and other health specialists are invited to a camp where they offer their services. These children are analyzed and solutions provided to the parents. These parents are expected to carry out the various therapies suggested at their homes and provide their feedback to the Federation on how the therapies helped. They are also asked to keep in touch with the therapists for further treatments and suggestions.

4. Medical Camps

Other than the health camp which deals with issues related to behaviour, therapies, language an learning and other social aspects, the Federation in association with a local parent support group also organizes Medical camps across the country. Persons with Down syndrome have many medical complications because of their condition. Therefore the children need the support of not only their pediatricians but also other specialists like the cardiologist, endocrinologist, opthalmologist, dermatologist, dentist, ENT specialists, psychiatrists etc.

During these medical camps local specialists are invited to check out the issues faced by persons with Down syndrome and they are then given the necessary consultation and medications. Since the doctors involved belong to the same area, it becomes easier for the parents to meet up with the doctor on a regular basis. These camps are usually organised in hospitals/clinics or in large halls where all the specialists are made available in an individual room. This becomes easier for a parent to open up to the doctor about their child's condition.

5. **India International Down Syndrome Conference**

The India International Down Syndrome Conference (popularly known as IIDSC) was started in the year 2017. The first IIDSC was done in association with the National Trust. The main goal of IIDSC was to bring the experts to one common platform for parents, caregivers, doctors, therapists and persons with Down syndrome to understand more about the condition and also to help them in providign a solution for the problems being faced by them on a regular basis.
In 2017, IIDSC was organized in New Delhi where the **UN** Resident Coordinator Mr. Yuri Afanasiev was the Chief Guest/. He himself is a parent of a person with Down syndrome. In 2018, the event was organized at Pune where the City Commissioner Mr. Saurabh Rao was the Chief Guest. This event was even aired on National Television. In 2019 the event was organized at Chandigarh where Shri. Rana Gurmeet Singh Sodhi Minister of Sports and Youth affairs and NRI affairs was the Chief Guest.

All these events were eye openers for parents and there were special programs organized for persons with Down syndrome too where they are expected to be a part of the conference.
In 2020, the event was planned in Raipur, Chhatisgarh, but due to the Lockdown across the country, the event was postponed.

6. Mothers Only Meet

Every year, the Federation organizes an event only for the mothers. Since mothers are with their children mostr of the time, they are under a lot of stress. Therefore, the President of the Federtion, Dr.Surekha Ramachandran decided to organize an event only for the mothers. This is a time for mothers to be free from stress and they have a lot of fun activities to keep them going.
This 2-day event is looked forward to by most mothers since they feel the need for a break to rejuvenate themselves and then go back fresh to face their families in a more positive environment. This year the event was being planned at Goa, but due to the Corona scare, this also has been temporarily rescheduled.

7. Financial and Social Support

The Federation gets a lot of requests from parents of childern with Down syndrome for financial assistance, primarlily for surgeries. In the last year itself 3 children with Down syndrome were provided financial assistance and support by the Federation to organize their surgeries.
Other than surgeries, assistance is also provided to parents in the form of Counselling and emotional support since it can be tough on a parent of a child with special needs. This counseling helps them to understand the needs of their children as well as themselves better.

8. World Down Syndrome Day (WDSD) Programs

The UN declared March 21 as World Down Syndrome Day since in this condition the 21st Chromosome Triplicates (becomes 3). DSFI organizes the WDSD programs all over the country with various activities that include rallies, sports events, seminars, marathons, cyclathons etc.

The WDSD events are arranged by the DSFI Parent Support Groups across the country. In New Delhi, National Trust also works in collaboration with DSFI to organize seminars to support the cause of persons with Down syndrome.

DSFI also encourages persons with Down syndrome by sending them to the UN Office at Geneva for the World Down Syndrome Day. This is not only a learning experience for them, but also a place where they can talk about their everyday life and struggles and how they overcome it. This was done in 2019 and was planned in 2020 also.However due to the COVID 19 issue, this has been postponed to next year.

9. Seminars and Webinars

Due to the Lockdown, we could not organize the IIDSC 2020 at Raipur as originally planned. Hence a 3 hour webinar was organized with various experts on the 28 of May 2020, which was the orginal schedule of the IIDSC.

DSFI also organizes seminars in various places to spread information about Down syndrome and also touches on various challenges that persons with Down syndrome face and how they can be surmounted

10. Down Syndrome Course

In 2019, DSFI started a course specific to Down syndrome in association with IRC Bangalore. IRC is a government recognized body that conducts various courses in the area of disability. The course on Down syndrome had various experience faculty come and share their ideas on Down syndrome. Since the course was organized only in Bangalore, there were 20 participants only in the course.

This year, due to the Corona threat, the Federation has decided to go online wiht the course. The course is starting on the 20th of June, Saturday and will be a 6 month course. This course aims towards all those who are keen to know more about Down syndrome and would like to assist and support persons with Down syndrome.

11. Support Programs

Our organization relies on its members to drive the support programs, and we believe that the strength of our community lies in its people and the relationships they build. That’s why we host numerous social and networking events throughout the year where members can renew friendships, lend support, share experiences, exchange ideas and meet new people. Whether you are a new parent looking for support from others or an adult looking for social events to attend, you will find what you need in our various social groups.

12. DSFI on International Platform

DSFI is also one of the founding members of the Asia Pacific Down Syndrome Federation (APDSF). APDSF is an International organization comprising the Down syndrome bodies of about 21 countries from the Asia Pacific Region.The main aim of APDSF is to support persons with Down syndrome in the region. The major countries who are members of the APDSF include:

1 Australia
2 Bangladesh
3 Bhutan
4 Brunei
5 Hong Kong
6 India
7 Indonesia
8 Japan
9 Malaysia
10 Maldives
11 Mongolia
12 Myanmar
13 Nepal
14 New Zealand
15 Pakistan
16 Qatar
17 Singapore
18 Sri Lanka
19 Thailand
20 UAE
21 Vietnam

DSFI has been supporting the APDSF countries in a variety of ways. They have participated in all the AGMs of the APDSF held so far. These were

2016 - Singapore
2017 - New Delhi
2018 - Colombo
2019 - Dubai.

The latest APDSF AGM held in Dubai in 2019 also had the President of DSFI, Dr. Surekha Ramachandran present for the meeting on behalf of India.

DSFI has been assisting the APDSF countries by providing support services for other countries. This includes providing looms for Nepal and also hands on experience in weaving, involving other countries in the course on Down syndrome which is being organized online and providing information assistance to the countries that need more information on Down syndrome. DSFI has also sent representatives to the United Nations on behalf of the APDSF to speak about various issues related to Down syndrome. This included a self advocate who spoke about herself and her dreams as a person with Down syndrome.

Report for Down syndrome Federation of India 2019 - 20

The year 2019-20 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, cyclothons where persons with Down syndrome went along with their parents and siblings, art exhibitions, and in Chennai, a rally was organized at the Elliot's Beach, Besant Nagar where persons with Down syndrome as well as others gathered in large numbers to talk about Down syndrome. The Chief Guest was Cine Actress Ms. Sai Pallavi, who being a doctor herself advocated Inclusion for persons with Down syndrome. At Delhi, a high-tea was organized with Mr. Nikunj K. Sundaray was the Chief Guest. He mentioned about issues related to persons with Down syndrome and said they would try and address issues like Disability Certificate and having Down syndrome as a separate disability

2. **Representation at the UN in Geneva –** Dr. Surekha Ramachandran, President, DSFI represented India at the World Down Syndrome Day celebrations of the UN at Geneva. The session was well attended and other speakers included the Indian Ambassador to the Permanent Mission in the UN, Mr. Rajiv Chander. Opening Remarks by Mr. Michael Moller, Director General of UNOG, Mr. N. Ramachandran, President, Asia Pacific Down Syndrome Federation, Indian self-advocate, Ms. Karishma Kannan spoke at the mission creating awareness about persons with Down syndrome and how they can do wonders when given the right opportunity.

Down Syndrome in India
Shifting Perspectives

Dr. Surekha Ramachandran
President – Down Syndrome Federation of India (DSFI)

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3. **Visit to Qaid-E-Millath College**- Dr. Surekha Ramachandran was a guest speaker at the QEM College, Chennai where she spoke to students about Down syndrome and inclusion. The students who had not even heard of Down syndrome were in awe when they were told

about the achievements of persons with Down syndrome. These students were so inspired that they came as a part of the WDSD Celebrations to the Besant Nagar beach.

4. **Camps across the country** – Medical and Health camps were organized at various locations across the country
    a. Bangalore – The camp at Bangalore was organized in association with the Parents Support Group of Bangalore. Rainbow Hospitals at Bangalore was the supporting partner and they had various Medical Specialists to check the various issues that children faced and provided them with medical support to each individual case. Counselling was also done for parents to create awareness about how important it was for them to understand their children with Down syndrome so that they could support and assist them in living up to their potential
    b. Hyderabad – At Hyderabad, DSFI in association with Nayi Disha, an organization for persons with disabilities organized the Health camp. a health assessment camp at Hyderabad, for children with Down Syndrome under the age of 20. Individuals with Down Syndrome are more prone to a specific set of health challenges that often go unnoticed due to lack of awareness. Early identification and intervention will ensure these individuals lead a happy and healthy life as they grow older. The camp brought together a team of medical professionals that included experts in the fields of Pediatrics, Audiology, Otorhinolaryngology (ENT speciality), Dentistry,

Cardiology, Orthopedics, Optometry, Occupational therapy and Physiotherapy, all under one roof. Parents also had the opportunity to interact and seek counsel from the Co-Founder and Chairperson of DSFI, Dr.Surekha Ramachandran who motivated parents to promptly address their child's medical concerns at the right age while inspiring them to identify and bring out the very best in every child. A total of 38 children were assessed by all the experts and medical advice rendered after examination of each child. The camp was a grand success where parents were able to understand and address their children's medical needs through a holistic approach

c. Delhi - more than 80 kids Down Syndrome Parents Society (DSPS) - Delhi a chapter of Down Syndrome Federation of India (DSFI), for the first time in Delhi/NCR organised a Health Camp for the Persons with Down syndrome. Over 100 children were registered for this health camp out of which more than 85% could actually turn up; making it a huge success for the 'First Timers'. A team of specialists consisting of Pediatricians, Endocrinologists from IAP, ENTs, Dentists, Occupational

Therapists, Speech Therapists and Special Educators participated in this event. Parents were able to discuss any and all discussed. Everyone was excited, happy to meet their extended family members. Even the volunteers loved the warmth of the little power houses – ‘Our Kids’The atmosphere turned into a celebration once the Hon’ble Minister of State, Dr. Mahesh Sharma, who was celebrating his 60th birthday, graced the occasion by spending quality time with the special children. He also announced that Down syndrome clinics will be operating in the Kailash Hospital. He mentioned that IMA & IAP will be supporting many more such camps in future. Also, present for the occasion were Dr. Arvind Garg president of IMA and Mr. Vishnu Kartik, CEO - Xperiential Learning Systems and Associate Director - The Heritage Schools, Ms. Nita Choudhary, Member of Central Administrative Tribunal Principal Bench, Mrs. Surekha Ramachandran, Founder and Chairperson - DSFI, Mrs. Rashmi Anil Joshi, President – DSPS

d. Coimbatore - The Awareness camp at Coimbatore was held at Geneomm clinic under the initiation of Dr. Pradeep, Geneticist to bring multi-disciplinary team comprising of doctors, counsellors, therapists, special educators and paediatric psychiatrist under one roof to help the children with Down Syndrome to get holistic rehabilitative facilities and intervention techniques. It was noted that people were from different occupation, family and territorial experiences and the effect on the children’s rehabilitation was very evident due to non-availability of facilities and also lack of awareness. Hence, the most unique and immediate plan of action in this camp was to create an active parent's WhatsApp group along with the rehabilitative team members, which was initiated and stressed by Dr. Rekha Ramachandran in her jolting talk, addressing the parent's group and the participating rehabilitating team. The children/persons who came for assessment were in different age groups starting from 1 year to 20 years approximately with varied backgrounds and needs. However, it was noticed that parents wanted their children to have basic functional education and were not aware about the inclusive education system and were not aware about the medical and therapeutic interventions needed for their children. Along with the stress on the inclusive education the children were assessed based on the checklist in the domains of motor, personal, academics, socialization and language development and were given few techniques to be followed to move forward in their learning. It was noticed that most of the children at the primary (9 to 11 years) age group were still being taught alphabets, under-estimating their potential. At the conclusion, it is very evident that these parents need continuous support system in medical, therapeutics and functional academics along with more openings for vocational pursuits. These people should be provided more opportunities to participate in sports and cultural events.

e. Raipur where the team from Chennai as well as the local medical teams were a part. The workshop at Raipur started off with an informal interaction with Dr. Surekha Ramachandran calling the children to join her on the stage, sparking a lot enthusiasm amongst the parents who let their children enjoy themselves on the stage. The effective planning and organization of the workshop by the volunteering team at Raipur was truly appreciable. They were able to provide a lot of motivation to the parents present at the event. Children and adults showcased a dance-drama and many children walked up to the stage with placards to spread awareness about Trisomy 21. The chief guest at the event was inspired by the spirit demonstrated by the children and the motivational interaction that Dr. Ramachandran had with the parents. Dr. Ramachandran used communication as a tool to ensure that the stakeholders and parents discussed the facilities needed and provisions required in society to help our children become a part of mainstream society. After the workshop, an individualized family counseling and assessment session was conducted by Dr. Rekha Ramachandran and her team to understand the current situation and conditions of the families and persons with Down syndrome. The team then suggested appropriate intervention programs to facilitate the family and person with Trisomy 21 to benefit from the available resources. Parents were also informed about ways to create an inclusive environment in the society to accommodate the children. Emphasis was laid on sport and physical fitness as a part of therapy. Swimming was focused upon as both a healthy and recreational activity. Training the children with appropriate reinforcements was discussed. Various home based strategies to learn functional academics, personal and social skills for holistic development was also touched upon with the parents. The camp ended successfully with all the stakeholders – the parents, persons with Down syndrome, the special educators and the government willing to put in the efforts to encourage and provide equal platform to ensure good health facilities and financial assistance for health care. It was a very good experience for the DSFI team whose commitment and support is now being sought after across the country to help persons with Down syndrome lead better lives.

These camps are now being requested across the country since they are very useful for the parents in grooming their children

5. **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. 3 Children were provided with help this year.
    a. Children with Down syndrome are prone to illnesses due to lower immunity. The most common complication that children face is heart related. Even at the time of birth many children have issues where doctors generally suggest early surgeries.
    b. The Federation keeps getting requests from various hospitals, parents and other doctors with requests for assistance for their surgery. The Federation then seeks the support of well-wishers to support the surgery of such children. Today the children whose surgery was supported by the Federation are all leading healthy lives.

6. **IIDSC 2019 –** The annual conference organized by DSFI – the India International Down Syndrome Conference (IIDSC) was held in Chandigarh this year from Sep19-21st.
    a. It was attended by almost 400 delegates including nearly a 100 self- advocates (persons with Down syndrome).
    b. 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.
    c. 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.
    d. The annual DSFI Excellence Awards were given to 2 self-advocates for their contribution towards creating awareness about Down syndrome through their confidence and social skills. Two winners were selected for their contribution to Down syndrome by being socially active in their endeavor to make persons with Down syndrome come to the limelight. They fought for the rights of persons with Down syndrome and made sure that their voices as well as the voices of persons with Down syndrome was heard.

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8. **Course on Down syndrome –** DSFI in association with various institutions is planning to conduct a course on Down syndrome. Meant for Parents, Therapists, Doctors, Students and anybody interested in Down syndrome, this course covers the various aspects of Down syndrome which a person needs to know to enable the empowerment of persons with Down syndrome. The first of this course is currently on at the IRC center in Bangalore. In Chennai, talks are on with Loyola college to offer this as a Certification program.
    a. This course began with the basic aim of providing information about persons with Down syndrome and answers to the basic questions that people have with respect to Down syndrome. The course was conducted by various doctors, therpaists, special educators and parents themselves who covered the various aspects of Down syndrome.
    b. The course was of 4 months duration and at the end of the course a viva was conducted by Dr. Surekha Ramachandran President – DSFI for all the students. Out of the 19 students who underwent the course 17 of them were provided with certificates while the others were asked to repeat certain aspects of the course in which they seemed to need more knowledge.