



**ASIA PACIFIC
DOWN SYNDROME
FEDERATION**



APDSF E-News

APDSF Newsletter

President Speak

Dear Members:

It is an honor for me to be writing the foreword for the first ever APDSF newsletter. The APDSF so far has been a loose amalgamation of like-minded countries working towards the same goal – an inclusive society for our children with Down syndrome. However, now that we are a registered body, our job has been simplified. We are now at a phase where we can demand for our children – from society and from our governments.

The Asia-Pacific region is tradition bound to age old customs even today. Even now, it is difficult for society to accept our children as they are. That is why we at the APDSF need to rally together and make our dream of an inclusive world possible. It is for this reason that we have started this newsletter. We will be getting information from the various countries, along with successes that each of us have received. This will definitely be of help to our brothers and sisters in other countries who can learn from our experiences.

I am really looking forward to support and suggestions from you all for the newsletter to become a tool that can help spread the message of inclusiveness and a binding force that will help our children being received by a more open society and world. Let us all make APDSF a stronger body that can reach out to more and more countries in our region and help make them more open about Down syndrome.



N. Ramachandran
President

From the VP's Desk



Dr. Lalita Joshi,
Nepal

I feel highly privileged and honored to be associated with Asia Pacific Down Syndrome Federation. It is indeed a nostalgic feeling when we all contemplate on the past history of APDSF. My heartiest congratulations to Mr. N Ramachandran and team for the zealous efforts which rewarded us with the formal registration of organization in Chennai, March 2017.

As Vice President, I look forward to working together and ensure APDSF to become more prominent and relevant, continue to add value for its existing vision of helping people with Down syndrome in the Asia Pacific region lead meaningful and productive lives with dignity. Medical and clinical research would be a priority to improve health and lifespan of people with Down syndrome. Studying the effects of triplication of chromosome 21, scientists can more handily identify causes and help formulate interventions and cure.

Finally wishing a grand success for 1st IIDSC 2017 and the 1st edition of APDSF Newsletter which would be a gold standard for information on DS both in Nepal and abroad.

Dr. Lalita Joshi (Rtd.Br.Gen.)
Vice President , APDSF



Mr. Angus Graham,
Australia

On behalf of Down Syndrome Australia, I am pleased to be associated with the formation of the Asia Pacific Down Syndrome Federation. It is vitally important that as a region we develop, share and encourage ideas, learnings and research to assist all those with a lived experience of Down syndrome.

Australia is pleased to help take its leading role as a member of the APDSF and very much looks forward driving continued collaboration both within the Asia-Pacific and further afield. The 'Three Pillars' of focus in Australia are, Education, Employment and Health & Ageing. These major policy initiatives tie in with the aims of the APDSF, being Healthcare, Community and Education. We at Down Syndrome Australia look forward to working with our regional neighbours in achieving our Vision, where people living with Down syndrome are valued, reach their potential and enjoy social and economic inclusion.

Let me finish by congratulating the Down Syndrome Federation of India in organising and hosting the 1st IIDSC 2017 which I am sure will be a great success.

Mr. Angus BL Graham OAM
Chairman Down Syndrome Australia
Vice President APDSF



Dr. Bhavani Sriram,
Singapore

It is a great distinction to be appointed to the office of Vice President of the Asia Pacific Down Syndrome federation ('APDSF'). The APDSF comprises of seventeen member states, spanning large parts of the Asia Pacific region. In my view, by uniting our strength and expertise, we can all work together to further our common goal of advocating for the rights of persons with Down syndrome.

The team has worked relentlessly to officially register the organization and I am indeed very proud to be a part of it. As a doctor, I have been involved with setting up a clinic focused on the healthcare needs of children with Down syndrome. I look forward to being able to contribute on a regional scale to achieving the organisational goals of the APDSF. Specifically, these are improved healthcare, education and community inclusion of persons with Down syndrome. Providing evidence based health care using standard guidelines and protocols will be my area of focus.

Finally, I would like to congratulate the organisers of the first India International Down syndrome congress and look forward to meeting as many of you as possible there.

Dr. BHAVANI SRIRAM M.B.B.S (India), M.R.C.P (Paeds) (London),
MINDS Developmental Disabilities Medical clinic
Singapore. Visiting Consultant, KK Women and Childrens' Hospital

Down Syndrome Association In Our Member Countries

- Australia

Down Syndrome Australia is made up of eight State and Territory associations providing support, information and resources to people with Down syndrome and their families across the country. The associations have come together to represent and progress the needs, interests and aspirations of people with Down syndrome and those that support them.

For more log on to <https://www.downsyndrome.org.au/index.html>

- Bangladesh

Down Syndrome Parents Support Group of Bangladesh is a joint initiative of AMDA Bangladesh and Japan Bangladesh Friendship Hospital, 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.

For more log on to http://www.amdabd.org/down_syndrome/index.php

- Bhutan

Ability Bhutan Society (ABS) is a public benefit organization founded on the recognition that persons living with moderate to severe diverse abilities, primarily children and their families have special needs. It was registered with the Civil Society Organization Authority of Bhutan (CSOA) under registration no: CSOA/PBO-15 on tenth of November 2011.

For more log on to <http://absbhutan.org/>

- Hong Kong

The Hong Kong Down Syndrome Association was registered as a non-profit making organization in October 1987. Committed to serving individuals with Down Syndrome, intellectual disabilities or other disabilities and their family members by providing them with integrated family support and vocational rehabilitation services is their main goal. They uphold a firm belief that people with these disabilities should enjoy all basic human rights and equal opportunity in our society. Creating a supportive and inclusive environment is thus very important which is what HKDSA stands for.

For more log on to <http://www.hk-dsa.org.hk/about/chairmsg/?lang=en>

- 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 Aabled, Government of Tamil Nadu under Section 52 of the Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act, 1995.

For more log on to <http://downsyndrome.in/about-dsfi.php>

- Indonesia

ISDI (Ikatan Sindroma Down Indonesia or Indonesian Down syndrome Society) was formally established on 21 st April 1999. A non-profit support group of parents, medical professions, special-needs experts, teachers, and all of those who have deep concern. Parents are very concerned of the future of children with Down syndrome in Indonesia especially when little is done to support them by the government or other non-profit organizations.

For more log on to <http://www.isdi-online.org/>

- Japan

Japan Down syndrome Society (JDS) is a non-profit organization committed to improving quality of life for people with Down syndrome and their families, and promoting their inherent right to be accepted and included as valued and equal members of their communities. There are about 5800 members in 55 branch groups as on Dec 2014. JDS branches all over Japan support in getting regional information about Down syndrome or kids with DS.

For more log on to <http://www.jdss.or.jp/e/>

- Malaysia

Down Syndrome Association of Malaysia (PSDM) was established by a group of parents of children with Down Syndrome and has been officially registered with the Registrar of Societies on 11 May 2001. Down Syndrome Association Malaysia is a Voluntary Organisation Welfare at national level caring for individuals with Down Syndrome and their families.

For more log on to: <http://downsyndromemalaysia.com/about-persatuan-sindrom-down-malaysia/>

- Nepal

DSAN has been actively involved in various Awareness raising programs in Schools, Colleges, Civil Service related Institutions / Organizations and in village Communities about various issues related to Down’s Syndrome, and also about characteristic recognizing facial and physical features of Down’ syndrome. They also give awareness and support individuals with Down’s syndrome through every stage of their lives and to achieve this we provide a broad range of services and support

For more log on to <http://dsanepal.org.np>

- New Zealand

The NZDSA, a charitable organisation is currently running its annual telephone fundraising campaign from the 13th June – 1st August 2017 to raise awareness and support its ongoing work.

This year their annual appeal is twofold:

First to host their annual Youth Development Camp at Vaughan Park Retreat Centre, Long Bay, Auckland focusing on building self-esteem, gaining independence and confidence, as well as some activities like rock climbing, archery and abseiling. The second is to publish and distribute their quarterly journal called CHAT 21.

For more log on to <http://www.nzdsa.org.nz/>

- Pakistan

Pakistan Down Syndrome Association (PDSA) is the only Non Profit Organization for persons with Down syndrome in Pakistan. PDSA is registered under Societies Registration Act, 1860. PDSA started its work led by Abid Lashari & his team from District Shaheed Benazir Abad (Nawabshah) Sindh Pakistan in 2009, to advocate for the rights of persons with Down syndrome in Pakistan. PDSA is a representative member of DSI.

The purpose of this DPO is to raise awareness about the rights of persons with Down syndrome in Pakistan. People are not aware about Down syndrome and its identifications. There are many children with Down syndrome in Pakistan and they are not visible to the public. People have hidden their children in their homes. PDSA is committed to make the people of this country aware of persons with Down syndrome and the promotion of rights of these people.

For more log on to <http://www.pdsapakistan.org>

- Singapore

DSA is a self-funded, non-profit Voluntary Welfare Organisation (VWO) which works closely and regularly with healthcare and educational professionals and other Voluntary Welfare Organisations. They are committed to:

- Provide support to families and caregivers
- Help a person with Down syndrome to lead a normal life and thus be able to contribute to society.
- Help integrate a person with Down syndrome into mainstream society

For more log on to <http://www.downsyndrome-singapore.org/>

- Sri Lanka

Every child is special to their parents irrespective of the appearance or any visible abnormality, than the normal child. In the present world we do not name them as abnormal. They also deserve a childhood and right to live in this world with out any discrimination. They all need some assistance to live, but they have their own abilities in different degrees. They may need therapy, extra help such as hearing aids or needs more special attention in different way. And this is what we would like to do for our children with Down syndrome

For more log on to www.geyef.org/jinendhi/index.html



News From The APDSF Region

Show them the world, and they'll exceed expectations, say parents of those with Down Syndrome

Three days a week, Quek Hong An, 31, wakes up early, all excited and prepped for work. He commutes to mushroom farm Edible Garden City in Queensway, where he learns how to prepare substrate for the mushrooms to grow. By most measures, Mr Quek leads a rather ordinary life – but for a person born with Down Syndrome, ordinary is good.

His family long ago decided never to let his disability define his limitations, and have been patiently providing him with every opportunity to learn, grow and get involved in anything that he takes an interest in.

Said his mother, May Quek, who refused to accept an expert's prognosis that he would forever be stuck at the mental age of five: "They can do so much more than what you expect, sometimes beyond your own expectations.

"Don't hide them in the house, and don't be afraid to show them off to the world. If people are patient with them, they can make a positive contribution."



Special Olympian Ms. Nadhrah's family

Ms Nadhrah's family also did everything they could to develop her strength and her confidence. Madam Ratna Daud introduced her daughter to swimming and bowling when she was young, as she thought that these physical activities would be good for both her physical development and her confidence.

The young go-getter is today a Special Olympics athlete, who bowled her way to an individual silver medal at the Special Olympics Summer Games in Athens in 2010. Ms Nadhrah Daud bowls, swims, and has interests like flower arrangement. Ms Nadhrah has also been working at McDonald's for two years now, for three days a week. It has changed her, said her mother.

For instance, at home she would take the initiative to help with sweeping the floor, doing the laundry or cleaning the table. "Working helps to give her confidence," said Mdm Ratna.

Before Ms Nadhrah was born, the mother of four admitted, she'd always pushed her other children to excel, especially academically. But with Nadhrah around, she taught me how to slow down and to appreciate my other children's achievements.

"While she cannot achieve as much as what normal children can, I am grateful for her small achievements," she said. "Any kid would have their own rate of development, so you should not compare."



News From The APDSF Region

Fighting Down's Syndrome with a Flourish

Ramnath finished school with flying colours and is now pursuing his BBA through distance education

Chennai: Usha Subramanian comes from a family that holds high faith in education and strives to raise children who love academics or become academicians themselves. So, when she walked her son Ramnath into the SIET Dyslexia Centre on his first day at school, her heart broke a little, knowing he wasn't welcome into the system that she had grown up revering. But to this day, she and her husband K Subramanian - both bankers -are grateful for their prudence in choosing to educate their son all the way through, when they could've easily succumbed to the prophecy of a doctor that he wouldn't live beyond the age of 18.



Ramnath who celebrated his 21st birthday on Monday says he loves studying as much as he enjoys watching Ajith films. The family saw its years of fighting naysayers pay off for the first time when Ramnath passed his Class X, with 94% and Class XII with 73%. Right from the year he finished Class IX, Usha spent her evenings getting additional notes from his class mates and taught him once again at home. Now, since he has started college, she has opted for voluntary retirement and spends time taking lessons for him at home, in addition to what he learns from a private educator. "She is equipped to get a degree in BBA herself," jokes Subramanian.

But this success didn't come easy. "The only person to keep our morale high was Ramnath's educator, Shivakumari, who pushed us to enroll him in a special school, at a time when we could've easily lost heart over the rejection we faced from several mainstream schools. This is pretty much the most crucial point for parents," says Usha.

China

Advocating for Down Syndrome Children in China

Abandoned children in China with Down Syndrome face a colossal uphill battle in finding a family within China. The stigma is so extreme these children are often labeled as unadoptable.

Bethany Christian Services has created the Bamboo Project, a dedicated focus recruitment effort to find families for children in China with Down Syndrome. To date 18 Bamboo children are home or have families pursuing their adoptions! A number worth celebrating! 40 darling children are still waiting for families however, including these beautiful faces. Families interested in adopting a child through Bethany's Bamboo Project often are able to start and finish their process in 12-15 months.

Raising the Bar Winning Accolades and Awards

A moving and inspiring documentary film by acclaimed Indian Director Onir, "Raising the Bar" follows six incredible young people with Down syndrome who meet at the World Down Syndrome Congress in Chennai India. What makes this story different is its raw honesty into the impact love, determination and the human spirit can have on one's life to overcome barriers.

This film extraordinary in how it portrays the ordinariness of its heroes, and it does this with humour and at times through challenging the audience in their subconscious bias.

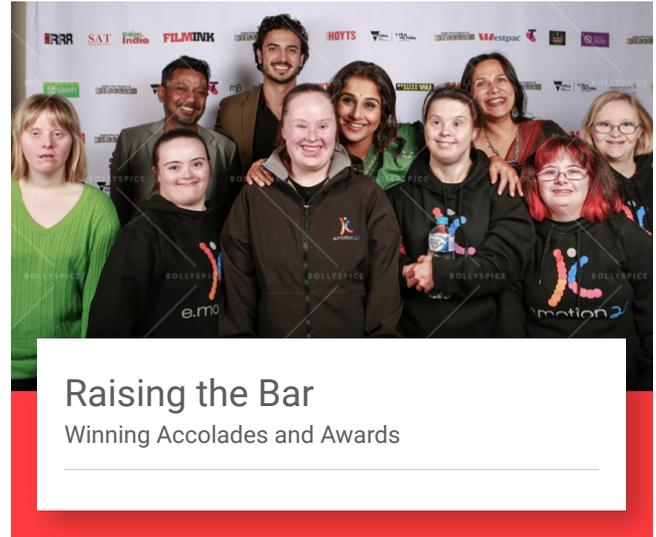
With an insight into vastly different cultures and communities across two continents, it inspires viewers to consider diversity in all of its facets, to create opportunities that embrace difference and to see what is possible when expectations are raised and people are given supportive environments in which they can strive and thrive.

The documentary has won awards globally including:

- Docs without Borders Film Festival - US - Spring 2017
Exceptional Merit (Human Spirit)
- Hollywood International Independent Documentary Awards US - December Award winner
- Spotlight Documentary Film Awards - US - Silver Award winner

It has also been selected for Official Selection at a couple of festivals

- Maryland International Film Festival - US
- The Ethan Saylor Memorial Film Festival – US



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