ASIA PACIFIC
DOWN SYNDROME
FEDERATION

APDSF E-News

APDSF Newsletter

President Speak

Season's Greetings!

When we started the APDSF Newsletter – APDSF E-News, our idea was that we reach out to the Down syndrome population across the Asia Pacific Region through our members. We were not very sure as to how this will be received, however, the support and the enthusiasm that each member has displayed as they send the news from their region – we are glad that this Newsletter has become an integral part of our activity.

APDSF is growing. This year's AGM has more members that in our previous edition. We have been joined by new members and we have countries that have expressed interest in being a part of the APDSF. This is good news for us. As mentioned, Asia Pacific region needs to unite to find ways to make life better for persons with Down syndrome. APDSF is trying to come together to share and disseminate information with each other.

This year, the Indian Down Syndrome Federation gifted a weaving loom to Nepal and also gave the basic training required to weave. This is just a beginning and all countries need to start associating with neighbours to ensure a better standard of living for all our children.

Christmas is the time for giving. Let us look at sharing with each other our knowledge to make this a brighter world for all persons with Down syndrome.

Wishing you all Merry Christmas and a Happy 2019 ahead!

“I am a Mother”

Juggling work and motherhood, says Rahayu Mahzam, is one of the biggest challenges she faces. But it is clear that the Member of Parliament for Jurong GRC, who is a lawyer, also enjoys her new role as a mother to her 16-month-old son, Ayden.

Ayden, is a person with Down syndrome.

Termination was never an option

Doctors first raised the possibility that Ayden had Down Syndrome when Mdm Rahayu was about five months’ pregnant. “It was very scary, because it wasn’t just Down Syndrome,” she explained. “There was a whole range of other issues, and also a possibility that the child may not survive pregnancy and childbirth.

“And when I asked the doctors if there was anything I could do about it, or if there is any treatment for the condition, they said no, but there’s an option for termination." But termination, she stressed, had never crossed her mind.

“I needed to tell my family so they could prepare themselves mentally, but I couldn’t handle their reactions,” she said, but ultimately, she is grateful for the support she got from her family members, who rallied around her and helped her out in ways big and small.

FINDING SUPPORT FROM FAMILY, SPECIAL NEEDS COMMUNITY

It was about three weeks before Ayden could be brought home from the hospital. But there was another part of the challenge: The constant medical appointments Ayden had to go for.

"It was so physically tiring, and there was work too," she said, explaining that she started work again "fairly early". She also started on her MP duties again, with Meet-the-People sessions coming in after a month, and market visits after two. She remains grateful for the family support that has continued even after she gave birth which helps build a schedule around both her and Ayden.

ON ADVOCATING FOR THE SPECIAL NEEDS COMMUNITY

Mdm Rahayu recognises that her role as a Member of Parliament has placed her in a unique position to be a voice for issues close to her heart. Such as, for example, the special needs community. She stressed that inclusive education – and a compassionate society – remains something that is close to her heart, and something she will continue to speak out about.

""I feel very fortunate and privileged to be given this honour to take care of him." We're doing our best to make sure Ayden is up to speed," she added. "But I really hope people won't make fun of him, dismiss him or take advantage of him.

"I hope the world will be a better place by the time he grows up."

I am like everyone else…

Don’t “hide them in the house”, but help them explore their potential, and they can contributing members of society, say families of eprsons 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.”

Mr Quek isn’t the only individual with Down Syndrome –to excel in their jobs and their passions, with the help of their parents, peers and employers. Ms Nadhrah Daud, for instance, is a bowler who has won silver for Singapore at the Special Olympics and works three days a week at a fast-food restaurant.

‘I AM NOT DIFFERENT’

Mrs Quek recalled the day her son was born. It was only then that the couple discovered that Hong An had Down Syndrome.“After I gave birth, I noticed that my husband’s face was not very happy. Then the paediatrician told me. “I didn’t know what to think. It didn’t mean a thing to me, I didn’t know anything about Down syndrome,” she said. A professor told Mary Quek her son would always have the mentality of a 5-year-old and that it would be best that he be sent to a dedicated home catered specially for his needs.

“It was really very discouraging but my husband and I, we did not give up. We believed that there is a future for (children like him),” she said.The couple never shied away from letting him participate in all aspects of community life. “He is like the rest of us, with all our needs and wants. “His interests are in cars, sports and in girls. From a very young age, he would chat up the waitress,” she laughed.

Mr Quek said that he likes to wash the family’s car, watch Youtube videos and drink coffee, adding: “I am not different. I am just like everybody.”

We fight for their right - Everyday

A WhatsApp group named “Delhi Trisomy 21” managed by Ranjan Sharma, 50, a professional photographer, is no less than a beacon of hope for parents, whose children are diagnosed with Down Syndrome. Ranjan’s hands remain in continuous motion to put an end to all the doubts aired by parents in that whats app group. It was after Ranjan’s 14-year-old daughter, Vilina, was diagnosed with down syndrome way back in 2003, when he resolved to help other parents.

”After this news broke out to us, my wife went into the state of depression,” says Ranjan.The couple was dismayed when the doctor broke into a statement: ”Don’t expect much from a child, she will remain in a vegetative state.”Amid the pall of gloom hovering over them, Ranjan was resolute in finding a way out and says, ”We searched a lot about this disorder and got in touch with many experts based abroad, who unlike many of Indian doctors, who just fire in the air,” added Ranjan.

Drawing out the conclusion from his experience, Ranjan went on to add: “Medical fraternity gives all the wrong information about this disorder, they paint a very gloomy picture.”

After 14 years of bumpy and yet enjoyable journey, the couple has successfully managed to smash the string of misconception pertaining to this disorder.

“There are very few doctors who know the intricacies related to Down syndrome,” said Dr I C Verma. Verma inferring from his extensive experience dealing with Down Syndrome said, “If proper care is given then the child can lead a normal life, but it is wrong to say that these kids can’t attain much in life.”

Telling their peculiar story, Kavita Baluni and her husband Himanshu Kakatwan, a software professional, said, ”Having a biological child was never on our mind, but giving home to one was always. At that time we made a resolution to adopt a baby girl with Down syndrome in India."

The journey of the duo in finding the 15-month-baby, Veda, with down syndrome was not less than a fortunate stroke. When Kavita and Himanshu started visiting hospitals frequently for Veda's treatment they had to grapple with the same set of problems all parents in India have to confront with.

Kavita, while summing up her troublesome experience with doctors said, "We took Veda to a hospital where well-known doctors after checking her thyroid level told us to take her home as everything was normal."

The couple, feeling anguished about the ignorance of doctors, says, "All doctors failed miserably in figuring this out that this level of thyroid is leading to aggravating problem, it was after becoming part of that whats app group that took us out from the web of apprehensions and apprised us that Thyroid level falling in normal bracket is abnormal for a child diagnosed with Down Syndrome."

Down syndrome is not a deterrent for her

Something special is going on in a classroom in the Shujaiya neighbourhood of Gaza city, and anyone lucky enough to be invited to sit in on a class is in for a unique experience. Watching the bond that is shared between young students and their teacher, Heba el-Shurafa, is inspiring; but it is more than just the usual student-teacher relationship. Heba connects with the children on a deeper level. She is a person with Down syndrome, as are they.

Having lived with the same genetic condition as her students, the 27-year-old teacher is uniquely placed to understand and meet the needs of her young charges.Using all the teaching aids she has at her disposal, classes are basic but interactive and infused with compassion and patience. Shurafa teaches the children maths, religious studies, Arabic, and how to recognise their names written on cards; plus science classes for children in the primary grades.

"I could not be happier. This place is comfortable and I love my students. I like how I say the words and they repeat them after me," Shurafa told Middle East Eye with a contagious grin on her face.

Shurafa's devotion towards her students is evident not only from the playful and caring way they all interact, but also from the fact that her composure never seems to waver. No matter how many times she has to repeat a lesson before they fully grasp it, she continues to go at their pace, knowing that she will ultimately be rewarded when she finally sees them comprehend her lesson and progress to the next level.

Stimulation is a key element in Shurafa's teaching plan. She has no qualms about encouraging them with treats like chocolate and dessert, as well as loud applause for those who try extra hard. Her colourful classroom is also decorated with balloons and streamers in the hopes of making their work environment more appealing to them.

The direction Shurafa's life has taken has not come as a surprise to those who know her. As a child, Heba’s eagerness to learn was evident. Her former teacher, Nawal ben Saied, who still teaches at the charity Right to Live Society - told that Shurafa has always been keen to learn and develop her life skills.

"She excelled in reading, writing, and counting. She could memorise songs, poems, and recite the holy Quran," ben Saied said. Her teacher added that Shurafa used to enjoy performing. She would sing, read poems, and perform plays on the school's stage.

Thanks to her family's lifelong efforts and the encouraging atmosphere Shurafa received during her developmental years both at home and in her school environment, she is thriving and is fully integrated into her local community.

Uniting for a Cause

A former TV Asahi Corp. announcer is working to raise awareness of Down syndrome in children. She has a 2-year-old boy with the condition. Freelance TV professional Airi Ryuen believes that to obtain support is the most important method to handle disabilities.

On March 21, she served as the moderator at several events focused on people who have the genetic condition. The United Nations has designated March 21 as "World Down Syndrome Day" because people with the syndrome have three copies of the 21st chromosome instead of the usual two. Ryuen, 39, who was born in Sweden, joined TV Asahi Corp. in 1999 as an announcer and from 2006 also worked as a reporter. Her partner works in a trading business.

She left the broadcaster in December 2011 and moved to California the following month, giving birth to a son in May 2013. Ryuen said she could not stop crying when she first found out that the boy had Down syndrome. But based on her experience of interviewing people, she said, she knew that whether one is happy or not cannot be decided by other people.

"I decided to raise him in a way that he would think of himself as happy," she said.

She launched a Japanese-language blog on March 21, 2014, when her son was 10 months old, to describe the U.S. welfare system and help to raise awareness about the condition.

She returned to Japan last year. Since November, she and has organized weekly gatherings for children with Down syndrome and their parents in Tokyo. In all, 100 families have taken part. Ryuen always tries to listen to mothers' stories and give them advice rather than pushing them to do something. She said the gatherings are aimed at sharing experiences and information.

At one such meeting, one mother wept, saying "I had no one who I could talk to." Ryuen said what she wants to tell mothers of children with Down syndrome is that they are not alone and that such children should be raised together. She said she will continue her activities in the hope of conveying it to society as a whole.

Moulding his dreams with Pottery

Doctors told Shaurya's parents that he would not be able to live a normal life. But his mother Neena Mehrotra was not someone who would let go that easily. When the doctors told her that he would not be able to do a single thing, it was like a bolt from the blue. She decided to challenge the notion. She refused to let anyone mould his story.

"I would like to go back to the doctor who prophesized that my son will do nothing. Today he goes to pubs and has a great time. He can drive a car and owns his own pottery studio. "Shaurya owns a pottery studio along with his mother – called Banana Studios. He has received training in pottery by artists from South Africa, Thailand and China.

His mother never forced him into anything. She always looked at what Shaurya was interested in and moulded him accordingly. When Shaurya was 19, the parents realized that he was fond of clay and colors. Pottery seemed to fascinate himself and seemed to be his preferred mode of expressing himself. He felt happy when he was with his clay and paints. His mother realized that he needed to meet more people and interact and thus was born the idea of the studio.

He loves making clay vehicles and vases. But it is the portraits that have gotten him acclaim. He has even organized exhibitions where sales have been phenomenal.

His mother says – "Shaurya might not be a brilliant kid, but he is a happy one and that is what matters!"