

A LITTLE EXTRA

Karachi Down Syndrome Program's Quarterly Newsletter

Advocating the value, acceptance and inclusion of people with Down syndrome in Karachi



VOLUME 2, ISSUE 4- JULY TO SEPTEMBER

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EDITORIAL

Hello Everyone! October – one of the most awaited months at KDSP - is finally here. Why is October so special to us you wonder? It's because October is recognized as the Down Syndrome Awareness Month. This latest newsletter issue has been especially designed keeping that in mind. In this issue you will find one of the most recent developments in the area of Down syndrome in Pakistan. We are delighted to bring you the news that two individuals with Down syndrome, who previously received training from KVTC, have been hired by Espresso! The KDSP publications team

was honored to meet them and this issue features an exclusive interview with the two successful individuals. The issue would also offer you with some ideas on how you can celebrate this month on an individual level.

Aside from this, the newsletter brings to you a quarterly round-up of the activities at KDSP, a poem written by a mother of a child with Down syndrome and a highlight on the recent medical development related to Down syndrome. We would like to extend heartfelt gratitude to all those who have thus far supported us in every program and helping KDSP improve every single day. Feel free to write to us with your feedback on publications@kdsp.org.pk.

Happy Reading!
Team at KDSP



What is the Karachi Down Syndrome Program?

KDSP is an organization formed by a group of parents and passionate individuals advocating the value and inclusion of people with Down syndrome in Karachi.

IN FOCUS

Sumit Raj is a 25 years old adult with Down syndrome. Owing to lack of awareness, he was unable to receive early intervention therapies required by every child with Down syndrome. As a result, he had limited speech ability. Watching all their other children lead a typical life, Sumit's parents often felt hopeless as they witnessed him being stigmatized by those around them. They wished he too would lead an independent, fulfilling life.

In pursuit of this dream, they enrolled Sumit at Karachi Vocational Training Centre (KVTC) where he received vocational training and basic education. Amongst the various programs there, Sumit found his interest in culinary skills. Besides cooking, he was a promising student academically and was also an active member of KVTC's cricket and football team where he proved to be a good athlete.

After the 3 and half yearlong training ended, Sumit was placed in an in-house job at KVTC for a year and half to further prepare him for employment in an external organization. After that period, KVTC's management contacted various organizations. Owing to stigma against individuals with special needs and a preconceived notion that they will be unable to perform in formal organizational settings due to their delayed intellectual development, not a lot of organizations were willing to offer him a place. The dedication and hard work of Sumit finally paid off when Espresso stepped up and took the initiative to not only hire him, but also hired Noman from KVTC who is a slow-learner and received training along with Sumit for seven years.

The two of them have now been working at Espresso since the past two months. Noman is a relatively shy person. He works at Espresso's corporate office where he responsibly performs routine service tasks and runs errands. Sumit, on the other hand is quite talkative and works at the bakery under the supervision of the baker. Since he likes experimenting, he bakes new items every day and eagerly invites his team members to taste his creations. Both Noman and Sumit expressed that they were happy with their workplace, the team they work with and enjoyed doing the tasks assigned to them.

Aliya, the Assistant Manager Human Resource at Espresso who has closely worked with both of these talented individuals said,

"Initially we felt that dealing with them might be a challenge, especially in terms of communicating with them. However, all our uncertainties vanquished when they became part of the team. Our team wholeheartedly welcomed them; so far no employee has faced any difficulty in communicating with either of them. Both have proven to be immensely diligent and we hope they keep up their performance." Gradually, the team at Espresso intends to enrich the potential of the two talented individuals by adding to their responsibilities and making them work independently.

The CEO of Espresso, Farooq Mamsa expressed his enthusiasm in continuing to hire individuals with special needs and adding more value to this process. "There is a profound stigma against individuals with Down syndrome and other special needs. This stigma exists merely because there is a lack of awareness; people are unaware of their talents. Only when we hire individuals with special needs will we be able to come out of the baseless illusion of their incapability as permeated by the stigma. We understand that such individuals have some needs that we as employers must cater to; but then employers do make certain provisions for their employees, so why not extend some provisions for them as well?"

We appreciate KVTC's unwavering determination in providing training and employment facilities to individuals with special needs. We also laud Espresso's one-of-a-kind initiative to promoting inclusion of individuals with Down syndrome and special needs by providing them dignified employment. Espresso has set an example for other local employers and we now hope to see other employers committing to provide individuals with Down syndrome and other special needs a chance to prove their capabilities!

CELEBRATE DOWN SYNDROME AWARENESS MONTH

October is National Down Syndrome Awareness Month. Down Syndrome Awareness Month is a time to promote the skills, abilities and talents of people with Down syndrome. It is another opportunity to dispel myths and to share the correct information about living with Down syndrome.

Help KDSP celebrate Down syndrome awareness month by stepping forward to play your part. Here are some ways you can celebrate Down syndrome awareness month:

(1) Learn about Down syndrome

With technology pervading every aspect of our lives, information about everything is a mere click away! Make use of this easy access to information to learn more about what Down syndrome is.

(2) Learn about the famous people with this genetic condition

Do you know about Madeline Stuart, the young girl with Down syndrome who catwalked the New York Fashion Week twice? Or about Lauren Potter, the actor from the famous TV show Glee? Use this month to find out more about individuals with Down syndrome who contend to break all stereotypes and touch the lives of those around them.

3) Advocate

Use #Down Syndrome Awareness Month to post on social media. Share informative articles, success stories, poems and updates related to Down syndrome within your community.

4) Keep the labels aside

Remember, labels are for jars, not for human beings. Labelling individuals with Down syndrome as disabled corroborates the preconceived ideas and stereotypes about them. Individuals with Down syndrome are differently-abled and are capable making worthwhile contributions to our society in their own unique way.

5) Open up your mind

Smile when you see a person with Down syndrome; don't gawk at them! Instead of categorizing them as 'others'; understand that they are more similar to us than different.

Myths Debunked!

Despite the incredible number of medical advances which have enriched and extended the lives of people with Down syndrome, Trisomy 21 continues to be extremely misunderstood. Many people look at Down syndrome through the lens of outdated stereotypes and misconceptions. Below is a list of some common myths about Down syndrome

MYTH: Down syndrome is a rare disorder.

TRUTH: Down syndrome is the most commonly occurring chromosomal condition.

MYTH: Down syndrome is hereditary and runs in families.

TRUTH: Translocation, a type of Down syndrome, is the only type of Down syndrome known to have a hereditary component.

MYTH: Most children with Down syndrome are born to older parents.

TRUTH: Most children with Down syndrome are born to women younger than 35 years old. However, the likelihood of having a child with Down syndrome increases with the age of the mother, especially after age 35.

MYTH: All people with Down syndrome have a severe cognitive disability.

TRUTH: Most people with Down syndrome have a mild to moderate cognitive disability, or intellectual disability, and is not indicative of the many strengths and talents that each individual possesses.

MYTH: People with Down syndrome are always sick.

TRUTH: Though people with Down syndrome are at an increased risk for certain medical conditions such as congenital heart defects, respiratory and hearing problems, and thyroid conditions, advances in health care and treatment of these conditions have allowed for most individuals with Down syndrome to lead healthy lives.

SPEAK OUT

MYTH: Segregated special education programs are the only option for students with Down syndrome.

TRUTH: Students with Down syndrome are included in typical academic classrooms in schools across the country. Increasingly, individuals with Down syndrome graduate from high school with diplomas, and participate in postsecondary academic and college programs.

MYTH: People with Down syndrome cannot be active members of their community.

TRUTH: People with Down syndrome are active participants in educational, social and recreational activities. They are included in the typical education system and take part in sports, music, art programs and any other activities in the community. People with Down syndrome are valued members of their families and communities, and make meaningful contributions to society.

MYTH: People with Down syndrome are always happy.

TRUTH: People with Down syndrome have feelings just like anyone else. They experience the full range of emotions. They respond to positive expressions of friendship and are hurt and upset by inconsiderate behavior.

MYTH: Adults with Down syndrome are the same as children with Down syndrome.

TRUTH: Adults with Down syndrome are not children, and should not be considered children. They enjoy activities and companionship with other adults, and have similar needs and feelings as their typical peers.

MYTH: Adults with Down syndrome are unable to form close interpersonal relationships leading to marriage.

TRUTH: People with Down syndrome socialize and have meaningful friendships. Some choose to date, maintain ongoing relationships and marry.

MYTH: Adults with Down syndrome are unemployable.

TRUTH: Businesses employ adults with Down syndrome for a variety of positions – in banks, corporations, hotels, hospitals, nursing homes, offices and restaurants. They work in the music and entertainment industry, in clerical positions, childcare, the sports field and the computer industry, to name a few. Like anybody else, people with Down syndrome want to have a job where their work will be valued.

Source: www.ndss.org. and www.themighty.com

Flat nasal bridge with small nose,
All children are flowers but yours is a rose,

Don't get upset with your child's facial features,
Guide them always; as you are not just their parent, but also their teacher,
Yes, they have small ears, They always love to play with their peers,

We all know they have a low muscle tone,
Yet they live happily in their comfort zone,

Their palm may have only one crease,
Always help them to live in calm and peace,

With broad hand with short fingers
They really love listening to songs by their favourite singers.

They have hyper flexibility,
But with the help of some techniques we can nurture their creativity,

Below average weight and length at birth,
Let's take a step with KDSP and make it all it's worth.

Ambreen Asif, Mother of Muhammad Ziyam Asif

TWO WORDS

Your birth brought us closer
As death lingered near
Your strength as you struggled
Gave flight to our fear

Down syndrome they whispered
Days after your birth
Two words that portrayed
A false image of your worth

Those words did not tell us
Of the love you would bring
Or the power your smile has
To make our hearts sing

Down syndrome didn't tell us
What kind of child you would be
Filled with amazing surprises
Shared with your father and me

Hard work, determination,
teaching and learning, it's true
Down syndrome means much of this
For each of us, not just you



HOPE

Parents of a child with Down syndrome,
Your life is not alone in a thunderstorm,

We all are here in a same boat,
If you need any help just remember the KDSP code,

Wonder child, spirited child
You've grown and you've thrived
Your every achievement
Still fills us with pride


No matter the voice used
Two words can't describe
The fullness you've added
To so many lives

Down syndrome, those frightening words
Whispered so long ago
Never did they prepare me
For the person I now know

Cheryl Ward, Poem source: <http://www.lit-teangels.gbr.cc/>

VOLUNTEER SPOTLIGHT

In search of a suitable organization to volunteer for, I was told about the Karachi Down Syndrome Program by a relative of mine. My first volunteer experience with KDSP was at the **World Down Syndrome Day 2016 carnival held at the **Beach Luxury Hotel**. It was one of my most memorable and enjoyable experiences; I was made to feel at home by the KDSP team and fellow volunteers with whom work felt like fun and time seemed to fly by.**



Since then I've volunteered for the 2016 Summer Camp, the Family Support Group sessions, and currently the Candy Club Sessions. Working with such bright, happy, and adorable children is a fulfilling and enjoyable experience that I struggle to even consider it as work. It's a pleasure in itself to see the smiles on their faces after completing an art project, while reading a story, or dancing to music.

These past months volunteering at KDSP have been absolutely wonderful; I've made friends, gained valuable insight, and worked with the happiest, most energetic children. Thank you to the KDSP team for making me feel welcome since day one, and for providing me with an experience I would not be able to find elsewhere.

Written by Simrah Faisal, student of O'Levels at Karachi Grammar School.

ACTIVITIES AT KDSP

Arts and Crafts for Adults – July

In the month of July, the arts and crafts participants made assorted animal keychains including horse keychains and elephant keychains.

Indie Arts and Crafts – July 17

The crafts of our very talented weekly arts and crafts participants were exhibited at the Indie Arts and Crafts Exhibition held on July 17, 2016. The total sales from this exhibition amounted to Rs. 18,000 which were then distributed amongst the arts and crafts participants who had put in their heart and soul into making those products with much finesse.

KDSP Summer Camp

KDSP hosted a summer camp for camp lasted from July 19 to August 2 and incorporated a range of intellectually stimulating activities for young minds. The movement and expression play sessions interweaved thematic stories with music which helped children develop their expressive skills, musical intelligence and gross motor skills. The sessions also introduced the children to various musical instruments and provided them with an opportunity to take turns to play a guitar. Some of the summer KDSP summer camp sessions were also conducted by Candy Club. In these sessions, the children participated in art based activities which revolved around science and mathematics. These exciting activities guaranteed learning and also helped strengthen the children's hand-eye coordination.

Family Support Group Session 19

KDSP hosted the 18th Family Support Group Session on the topic "Communications in Children with Down syndrome." on July 23, 2016. The guest speaker of the session was Sadaf Shahid. The session was attended by 40 parents and caregivers.

Pyar Ki Boli Auction

An online fundraiser auction titled "Pyar Ki Boli" was held on August 31, 2016. The famous TV actor Gohar Rasheed came forward to volunteer to auction his shirts worn in a famous TV serial "Mann Mayal". KDSP was successful in raising a substantial sum all thanks to its supporters!

Arts and Crafts for Adults – August

During August, the participants made green and white wristbands with nimbly crafted star and crescent to commemorate Independence Day. Apart from this, they continued making animal keychains and also began making beautiful flower vases.

Family Support Group Session 20

The 19th Family Support Group session was held on August 20, 2016 on the topic Occupational Therapy in Children with Down syndrome. The session was conducted by Nausheen Gul, occupational therapist and program coordinator at Milestone Charitable Trust.

Storytime with DramaMama

Storytime with DramaMama was back at KDSP in August. Hiba Masood engaged the young audience with stories on Pete the cat. The interactive stories were interspersed lots of enjoyable music, dance and role playing, leaving the children yearning for more!

Candy Club – September

After the success of candy club sessions during the KDSP summer camp, KDSP started holding regular Candy Club sessions from September 03, 2016. Activities involved making structures using marshmallows and straws. The activities centered upon enhancing children's hand-eye coordination and fine motor skills.

Arts and Crafts for Adults – September

In the month of September, our very talented arts and crafts participants continued working on flower vases. They also added some new animals – ducks, bears and birds – to their repertoire of assorted animal keychains.

Family Support Group Session 21

The 21st Family Support Group session was held on September 17, 2016 on the topic "An Introduction to Oral Placement Therapy (For Speech Clarity and Feeding)." The session was conducted by Rohma Nadeem Akhtar, a speech and language pathologist.



Arts and Crafts for Adults – July



DramaMama

ACTIVITIES AT KDSP



Arts and Crafts for Adults - August



Candy Club



Family Support Group Session August



Family Support Group Session September



Family Support Group Session July

HEALTH AND DEVELOPMENT

Teaching Mathematics to Children with Down Syndrome

Knowledge about basic mathematical skills is essential for independent living. Although the achievement of children with Down syndrome in mathematical skills is limited as compared to their achievement in literacy, research indicates that good teaching, effective visual learning aids and piquing children's interest in mathematics can spur their progress in this realm.

Language skills are related to achievement in number skills in children with Down syndrome. Strong correlation between verbal ability and number skills. However, children with Down syndrome develop and understanding for numbers in a different way as compared to typically developing children.

Children with Down syndrome enjoy social situations. Therefore, by teaching mathematical skills in an integrated social setting can be conducive to their learning of number skills. For instance, the concept of quantity or the idea of 'more' can be introduced at an early stage. This idea can be introduced to them for instance while eating to teach them to ask for more of something or while playing. Children as young as 18 months can learn this and use it to fulfil their needs.

Research has found the matching technique can also be very useful. The technique involves matching a numeral written on a card to an identical numeral on another card. Begin with one numeral to match — small steps allow the learner to succeed at each stage and practice before moving on. As one numeral is learned move to others. The order, however, is not important at this stage. In this process, selecting can prove to be more difficult for a child. When given some numerals, the child selects the target numeral when the teacher asks for it. Finally,

naming is the stage where the child names (or signs) the numeral when shown the card.

Additionally, here are some tools that can be used to enhance mathematical understanding and number sense:

- Abacus
- Number puzzles
- Lego
- Counting beads
- Early math books for children
- Specially designed phone/tablet apps

Source:

Number and arithmetic skills in children with Down syndrome retrieved from Australian Journal of Education and Development Psychology.

www.down-syndrome.org

Number skills development for infants with Down syndrome (0-5 years) retrieved from <http://www.dsacc.org/downloads/parents>

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