

# A LITTLE EXTRA

Karachi Down Syndrome Program's Quarterly Newsletter

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



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## EDITORIAL

Happy summer, everyone! A very warm welcome to a fresh issue of A Little Extra! The past quarter had been busy with the launch of the Down Syndrome Clinics in collaboration with Aga Khan University Hospital. We're happy to announce that many families have successfully been able to benefit from this collaboration.

This issue of A Little Extra will highlight the inspiring stories of families children with Down syndrome. Each story is replete with positivity, and a strong determination to shine against all odds. We are grateful to all the parents and caregivers who share their inspiring experiences and lovely photos with us. Keep them coming! The issue also features activities held at KDSP in the past quarter – including our fun filled summer camp for children and a workshop held in collaboration with Special Olympics Pakistan (SOP). We hope that this newsletter leaves you updated and inspired.

Write to us about what you liked, disliked or wish to see more of in this newsletter on [publications@kdsp.org.pk](mailto:publications@kdsp.org.pk). We would love to hear your views!

Hope you enjoy the rest of your summer!

Best Wishes,

KDSP Team.



Karachi Down Syndrome Program

"A company set up under section 42 of the Companies Ordinance, 1984."

## 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**

# SPEAK OUT

## *My Incredible Son Abdullah*

Born with the slanting eyes, my son was suspected of having Down syndrome since birth. At 2 years of age I received his karyotyping results, confirming that he had some extra chromosomal material (not the whole chromosome 21), termed as Robertsonian Translocation in Down syndrome.

Although as a baby all his milestones were delayed, he primarily had speech delay. This was the only apparent "problem" that made others point fingers at him and ask intrusive questions that were often even hurtful.

When he was 3 years old, my already crumbling marriage broke down completely. Abdullah and I came to live with my parents and my hunt for a school for him started.

It was very difficult to find a speech therapist in Multan at the time, since this was a new city for me and I didn't know many people here. I eventually found a therapist and started taking him to her. Unfortunately, 3 months later I discovered that she was a quack. As a doctor, I knew his speech delay could improve in an inclusive environment which is why I was strongly against sending him to a special education school system.

Over the next 6 years, my struggle to find an inclusive educational institution in Multan proved futile. A majority of the schools turned him down, some even saying that "other parents will not allow his influence on their kids" or "we don't deal with special kids because that's not in our policy". Ultimately, Abdullah did start going to a playgroup in a well reputed school.

I cried many a sleepless nights and struggled days on, trying to find help he needed. Even looking for any institute or therapist that could teach the tiny things he needed to learn, things we all take for granted like holding a pen or playing on a slide etc. yet there seemed no help in view.

Eventually, I learned to teach him myself, often with the help of Google. The journey thus far has been incredible - tiring yet tremendously rewarding! During his nursery years, I met with an amazing teacher who was self-taught about special education because her own son had a cochlear implant and struggled with hearing. She provided me with the extra help I needed with Abdullah's learning and sitting with regular kids in a regular school environment did wonders for Abdullah as his speech started to improve.

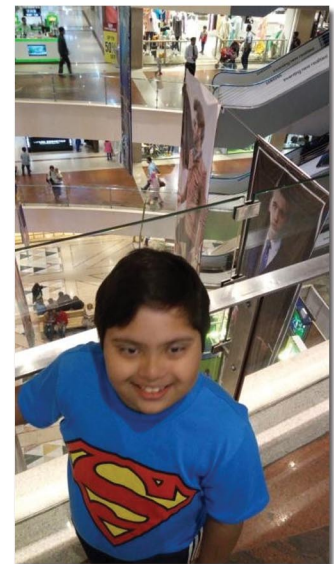
Last year, for first time in Multan an IB Curriculum school started and Abdullah was taken in with open arms there. Every single person in this institute is an advocate of inclusivity and caters to the fact that all children learn differently. My son has found his match; my struggle has taken a different shape but no doubt all struggles, great or small, always lead to success only.

As a Family Physician and a mother who has taught her way up with teaching and learning strategies of differently-abled kids, I plan to start a platform for all struggling families here in my city, just to guide them to the endless possibilities their children have.

Abdullah has always been a bright young kid, with intelligent sparkling eyes and huge smile. He is loved by all equally, from random guards and shop keepers on streets to everyone in family young or old. He is a happy, healthy, smart child who has a long way ahead of him to explore and excel in this God gifted journey called life. He proved his unlimited learning potential in Grade 1 and recently got promoted to Grade 2. He is the most loved child in school, the testimony of this I find every day when I go to pick him up and all the kids are cheering him like a celebrity. He totally amazes me. He is fond of all outdoor games, taekwondo, arts and crafts, gardening, swimming, singing and dancing and so much more. He is learning Urdu, English, French and Arabic languages and wishes to become Formula 1 driver one day. He brightens up my life so much that mundane troubles seem trivial.

Not a single bit of this adventurous voyage that Abdullah and I are on is easy. He does have learning limitations and struggles with them continuously, but he's a patient and a brave learner whose perseverance I admire and whose laughter strengthens my belief in Allah Almighty's plans.

***Written by Dr Attia Sheikh works with CMH Multan Institute of Medical Sciences and is a devoted single mother of Abdullah.***





# SPEAK OUT

## *My Journey as a Mother of a Child with Down Syndrome*

It was September 21, 2014 when I delivered my cute son, Zaid Kashif. Back then, I was unaware of the new journey I was about to begin. Initially, I couldn't tell that Zaid had Down syndrome – he did have a heart problem and got ill frequently, but there was no other issue. Later, I started noticing delays in his developmental milestones. This led me to become concerned rather than disappointed. I was ready to do everything I could to make him feel better and accelerate his development.

I finally came to know that Zaid had Down syndrome when he was 11 months old. Even when I came to know of this, I was more concerned than disappointed. I did not know where to go, what to do. I was eager to discover information and resources which would be beneficial for my child.

It was then that my sister told me about KDSP. When I visited KDSP and met with their staff, it was a dream come true! This was the kind of platform and support I had been looking for myself and my child. I can now confidently say that there is nothing that disappoints me about my son! His heartwarming smile and his hardworking nature makes me very happy. I'm so proud to be his mother and I'm so lucky to be associated with KDSP. I wish there more people to think about these amazing kids. I wish we had amazing facilities for children with Down syndrome in my home town Hyderabad too. I want to tell all the mothers with these little flowers of Jannah (children with special needs) that you have been chosen to be a proud mother, and you should never get tired of this

amazing journey. May Allah make us all more strong and happy with our little ones. Ameen.



***Written by Naveen Kashif, Mother of Zaid Kashif.***

## *My Son, Muhammad Hassan*

My son Syed Mohammed Hassan is my first baby, and therefore he is very special to me and my family. He possesses a unique quality of imitation. He is a master of imitation and has wonderful observational skills. He possesses a keen interest in music, especially Qawaali. He is an obedient, loving child, with an astounding academic record. I have had a tough time due to his medical issues, but now he is fine and I pray to almighty Allah that may He always shower His on Hassan. Ameen.

***Written by father of Mohammad Hassan.***



# SPEAK OUT

## *My Beloved Brother*

My brother, Mohsin Siddiqui, was born on December 30, 2003. He is the sparkle of my eyes and the sunshine in my life. Mohsin is the youngest amongst us 8 siblings, and I love him the most.

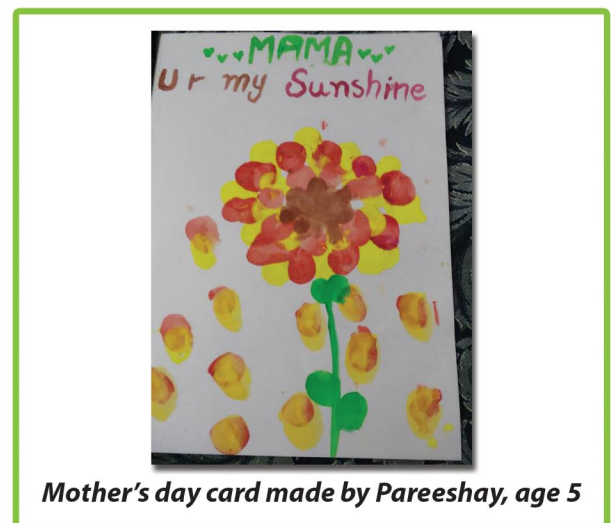
When he was born, no one was aware of the fact that he had Down syndrome. Once, my parents felt that he was experiencing some issue in breathing. My mother then took him to the nearest doctor. After a checkup, the doctor informed that Mohsin has two holes in his heart, and a fewer chromosomal count than normal.

My mother became worried, and immediately informed my father who was residing in Tokyo at the time. My father asked my mother to move to Tokyo. Our whole family then departed for Tokyo. There, Mohsin received proper treatment and medication. He underwent a major heart surgery. I still remember when he was first brought home and was in my mother's lap. I think my mother told me that perhaps he will open his eyes in 24 hours – but I don't exactly remember.

Alhamdulillah, Mohsin is now doing well. He goes to school here in Tokyo, and is able to do his every work independently; all he needs is a little guidance.



***Written by Eesha Siddiqui. Sister of Mohsin Siddiqui***



*Mother's day card made by Pareeshay, age 5*



# ACTIVITIES AT KDSP

## Young Athletes Program

KDSP has partnered with the Special Olympics Pakistan (SOP) to conduct sports training for children aged 5 and above. In the first series of workshop held on April 29, 2017 at Avari Tower Hotels, the parents were trained on how to conduct sports training with their children at home using recycled materials.



## Family Support Group Session

The 26th Family Support Group was held on May 27, 2017. The topic for the session was "Issues Faced by Siblings of Individuals with Down Syndrome". The discussion on the topic was led by Dr. Ayesha Mian, Associate Professor at AKUH, Diplomate, American Board of Child & Adolescent Psychiatry MBBS. This enlightening session was attended by 30 parents and caregivers.

## Arts & Crafts for Adults

KDSP welcomed its new group of participants in the last quarter. The arts and crafts sessions now cater to two groups – advanced classes led by Mr. Ussama and beginners' classes are led by Mrs. Mahtab Tariq.

For the beginners' module, Mrs. Mahtab introduced the basic skill of needle holding, maneuvering and stitching. The participants put this skill to practice by creating beautiful keychains, bags and fans.

Under the guidance of Mr. Ussama, the advanced arts and crafts class participants perfected their weaving skills, and made small rugs and cushions.



# ACTIVITIES AT KDSP

## Yoga Classes

Ready, set, stretch! Our participants have an enjoyable time at the end of each week stretching their muscles and conducting various exercises to help themselves relax. The classes are conducted by Ms. Azmat, a yoga passionate and a professional yoga instructor from Special Olympics Pakistan (SOP).



## Summer Camp 2017

The fun filled summer camp was held at KDSP from June 6, 2017 to June 22 for children between the ages 4-12. The camp was divided into three classes – movement classes, cooking classes, and arts classes.

The movement classes were conducted by Mr. Heera from BodyBeats Events and PR (BBPR). The children danced to rhythmic tunes and nursery rhymes.

The cooking classes were conducted by Ms. Rumana, a home-based food entrepreneur. Our little chefs took great interest in making scrumptious food salads, sandwiches, nutella pinwheels, coconut balls, and strawberry smoothie. The activities also aimed to strengthen the children's fine motor skills.

The arts classes were conducted by the Candy Club team. Here, the children had a wonderful time discovering their hidden artistic talents as they engaged in hand-casting, block printing, and tie & dye t-shirt printing.



# Volunteer Spotlight

I've always found personal pleasure in interacting with children that have Down Syndrome. At the beginning of 2017, I was in search of an organisation where I could volunteer and that's when I came across Karachi Down Syndrome Program.

My first involvement in one of KDSP's events was at the World Down Syndrome Day Carnival, 2017. It was a very different, heart warming experience, interacting with the children as they enjoyed various activities. Watching some of them dance away to the music and have the time of their lives was an experience of its own and made my heart so full.

I also volunteered at KDSP's Summer Camp for children aged 4-12. This summer camp gave me the opportunity to take a deeper look into the lives of children with Down Syndrome. I got to learn so much not just about Down Syndrome but also the individuals themselves and their capabilities. Not all activities went by perfectly. There were some bumps along the way when children got frustrated or struggled with completing a task but that too was a pleasure in itself, as we watched them figure out situations on their own and get a project done.

It isn't just the children at KDSP which make every event memorable, but also the encouraging parents and passionate staff that put up such great events and make everyone feel welcomed. So far, my journey of volunteering at KDSP has been an experience like no other and I would love for this journey to go a very long way.

***Sonia Golwalla, student of Beaconhouse School System.***





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