

# A LITTLE EXTRA

Karachi Down Syndrome Program's Quarterly Newsletter



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

Volume 3, Issue 4 | July 2017 to October 2017

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## EDITORIAL

**Hello Everyone!**

Hope the past quarter has been just as busy and exciting as ours has been! From launching a brand new early pre-school program for toddlers with Down syndrome, to developing IEPs for children admitted into mainstream schools, to adding value to existing enrichment programs at KDSP - it's been a delightful journey!

The current issue features beautiful write-ups and photos of individuals with Down syndrome and their families. The issue also presents a round-up of the activities at KDSP in the last quarter. As always, we're grateful to the families who take ownership of this newsletter by sharing their experiences with us. Please do keep them coming!

The publications team at KDSP is receptive to new ideas and constructive feedback by readers of "A Little Extra". Feel free to pour in your thoughts by writing to us on [publications@kdsp.org.pk](mailto:publications@kdsp.org.pk)

**Happy Reading!**



Karachi Down Syndrome Program

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

## WHAT IS KARACHI DOWN SYNDROME PROGRAM?

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

# SPEAK OUT

## DANIYA - THE APPLE OF OUR EYES!

-Ayesha Mahmud, Mother of Daniya

I would like to introduce my daughter, Daniya, who is 11 years old. We live in West midlands, UK. She goes to a local, mainstream secondary school and attends year 7. She is a busy bee and apart from school she has swimming lessons twice a week, football once a week, and past summer was going for inclusive cricket sessions as well. She is learning to ride a horse and she is learning how to ride a bicycle as well. Oh! I forgot to mention that she also attends drama, dance, and sports club on the weekends at our local Down syndrome club called Ups of Downs.

Daniya is cheeky, determined, confident, and friendly. She loves to dress up! Food is her big love, which of course, includes eating out. TV, computer, Ipad or gadget of any sort are her favourites. Two days into secondary school and she wanted a phone of her own! She talks incessantly, is truly bilingual, and without her our house is so quiet. She went on a four-day residential trip with her class and time just dragged in her absence. She is bossy by nature and orders her younger brother around constantly.

All of this has not come easily but she has worked hard with us on achieving this. When she was born she was unwell in the first month, but after that we have been very lucky. Apart from regular checks and routine appointments we have managed to

avoid hospitals. We have tried to introduce her to all the activities we could manage to offer her. From baby signing, speech & language, physiotherapy to starting nursery as a two-year old to help stimulate her as much as we can. It is an ongoing process, and the challenges have changed with time.

We have been blessed with a very supportive family who, despite being so far away from us, has been our strength. Despite the support it has been a very difficult journey, especially during the initial years. It takes time to accept that your child needs, and will always need, extra support, which leads you to feel over protective towards them. There is support and awareness in UK, along with legislation which is there to protect the rights of differently-abled people. However, the system does not always run smoothly; it requires time, effort and at times endless paperwork. I decided to stay at home and devoted my time to making sure she gets all the opportunities. Even now that she has grown up, I work part time to be there with her as much as possible.

I would like to say to all the parents of little ones, to try and enjoy every stage as much as you can. Be proud, be proactive in seeking new interventions and exploring new ideas, and above all be advocates for your children!



# SPEAK OUT

## MY SON ZIYAM

-Ambreen Asif, Mother of Ziyam Asif



My son, Ziyam, was born with Down syndrome. Life as a mother with a child having Down syndrome is indeed busy, with extra appointments and therapy every week. Even then, I don't consider extra responsibilities as a burden. It has become my pleasure and happiness to see him growing day by day.

I do not feel that he is different from others and someone to be compared of. As I have observed, he is not different from his other sisters. I would like him to be a well-rounded individual with morals, values, and compassion for others and I certainly believe that he will be.

I pledge here that I will do whatever it takes for him to be happy and successful in life as it also leads to my own happiness.

## I AM A "SPECIAL" MOM

-Bushra Usman, Mother of M. Awais

8 months earlier I never understood why the word "special" was used to refer to individuals with Down syndrome. When my baby boy, M. Awais, was born with Down syndrome 8 months ago, I came to realize why they are "Special".

Awais lights up our house as no one else does! When he smiles, I feel like the luckiest mother ever. Whenever he learns something new, our entire family is filled with joy and feels special – that is why, Awais is special! Being a mother of a child with Down syndrome makes me feel special and fills me with happiness.

I am grateful to my husband who gave me the courage and

support throughout this journey, and for loving Awais just as he loves our baby girls. We have never felt any difference between Awais and the other two typically developing daughters of ours – he can do everything his sisters can. I think parents of children with Down syndrome never feel any difference between their child with Down syndrome and their other typically developing children, I don't understand why the society always looks at them differently.

My husband and I are proud to be Awais' parents! We are thankful to Allah for blessing us with the cutest baby. To all the parents of children with Down syndrome, I would like to say that all of are truly blessed and special indeed!



# SPEAK OUT

## NO DIFFERENT THAN US

-Fariha Shirazi, Mother of Aiman

Sometimes in life you encounter unexpected experiences. Some of these experiences end up shattering you; making you feel like the unluckiest person in the whole world. You feel completely broken. I experienced a similar feeling when my daughter, Aiman, was born with Down syndrome on December 21, 2003.

Initially, there appeared nothing different between her and my elder daughter. I always wished that the doctor too would say that there is nothing wrong with her, and that she's just like any other typically developing child. It took me more than six months to accept the reality that my daughter had Down syndrome, and to accept my daughter the way she was. I was fortunate enough to find people around me – my friends, and family – who supported me in many ways. Soon, I began to realize that yes, Aiman is different, but she is different in a special way! She holds a special place in my heart, and is a child full of joy. She is loved by everyone and knows how to initiate endearing interactions with people who approach her. I can proudly say that she is better at social interactions than any other of my children. For me, Aiman is a blessing in disguise. Initially I was apprehensive about her future; but now, her loveable acts wash all my worries away!

Aiman is an extremely blessed child in every way one could expect her to be. She is fortunate to be loved by everyone. She has never make us realize that she is any different from other children. She loves to play with cellphone and laptop, and knows very well how to send out messages. When she was younger, I was always worried about her schooling. I was the happiest person when she was accepted into a mainstream school. She studies the same curriculum as any other typical child. At school, Aiman learns new words and always surprises us with new words every single day! I was beaming with joy when her principal told me that she was a source of pride for her school!

Aiman also loves cycling and skating. She spends her free time watching jeeto Pakistan. She also takes joy in baby sitting, playing games on mobile phone. Aiman also helps us in household chores although she always tries making excuses to avoid them.

Before I conclude myself, there is one thing that I want every parent with a child having Down syndrome to know: We can't

make generalizations about children and there is no need to compare one child with another, as each child is unique in their own way, and that is what makes them talented! Every child with Down syndrome needs a chance to flourish and to shine. They can accomplish just as much as any typically developed child can, and there is nothing to worry about.



# CATWALK DEBUT

## FOR TEENAGER WITH DOWN SYNDROME

A teenager from Cookstown, County Tyrone, is preparing to become the first model with Down's syndrome to take part in Belfast's biggest fashion event.

Kate Grant and her mother, Deirdre wants to challenge the perception of beauty and shine a light on and give motivation to a people with disability facing discrimination.

Mrs. Grant posted on Facebook explaining her daughter's desire to walk the catwalk.

"She has the same aspirations as any other girl who wants to be a model," she wrote. "Please support her. Just maybe her dream will come true."

Speaking on BBC's Talkback programme, Miss Grant told listeners: "I want to be everywhere, all over the world, because I am brilliant." "I want everyone to see me and I'll hold my head high."

Source: [www.bbc.com](http://www.bbc.com)



# COLOUR SPLASH



# ACTIVITIES AT KDSP



## ARTS AND CRAFTS

KDSP welcomed a fresh cohort for the beginners' module. The new participants learnt how to hold needles and adroitly maneuver it to make different patterns. Using this skill, the participants made lovely stuffed animals and key chains.

In our advanced arts and crafts sessions, the participants used colourful wool and cloth to weave beautifully patterned rugs.

## LAUNCH OF EARLY PRE-SCHOOL EXPERIENCE PROGRAM (EPEP)

After months of planning, research, and hardwork, we are pleased to announce that we have formally launched an Early Pre-School Experience Program (EPEP) for toddlers with Down syndrome between 1.2 to 2.5 years. The Early Preschool Experience Program (EPEP) is a one year program especially designed to prepare a child with Down syndrome and their parents for a confident, productive, and smooth transition and settlement in an inclusive school environment in later years.

The KDSP Preschool aims to provide for your child a relaxed, happy and secure environment in which he/she can develop socially, mentally and physically through structured educational play, therapies and activities. The main goal is to help the child interact with other children, learn to share and play along with getting familiarized with the basic skills like numbers, colors and shapes etc. In addition, their gross and fine motor skills, self-help habits, language and concept development will also be given special focus.



## TEACHER'S TRAINING WORKSHOP

A training session for all teachers of KDSP's partner schools was held on September 27, 2017. The online training session for teachers of KDSP's partner schools was conducted by Professor Sue Buckley from Down Syndrome Education (DSE), UK. Ms. Buckley is acclaimed to be the pioneer in promoting the best practices in inclusive education. The training session enlightened the teachers on how to develop reading and numeracy skills in children with Down syndrome in an inclusive classroom.

## FAMILY SUPPORT GROUP SESSION – AUGUST

The 26th Family Support Group session was hosted by KDSP on August 05, 2017. A discussion on "The Importance of Physical Therapy for Lung Development of Children with Down Syndrome" was led by Dr. Zehra Habib. Dr. Habib is credited to be the only PhD in physical therapy in Pakistan, and currently serves as a lecturer and practitioner at the Aga Khan University Hospital (AKUH). 37 parents and caregiver benefited from the session.





# ACTIVITIES AT KDSP

## FAMILY SUPPORT GROUP SESSION – SEPTEMBER

A Family Support Group session on the topic “Behavioural Issues Faced by Individuals with Down Syndrome” was held at KDSP on September 16, 2017. Ms. Ismaa Khan, a Behavioural Analyst, with 12 years of international experience in ADealing with behavioural issues of children with special needs, addressed some of the most pressing behavioural concerns parents had about their children. The session was attended by 40 parents and caregivers.



## STORYTIME WITH DRAMA MAMA

Storybook characters came to life with storytime session with Hiba Masood from DramaMama on October 14, 2017! The children were engrossed in comical actions of story characters, while singing and dancing to nursery rhymes in line with the story themes.

## PLAYTIME WITH GYMBOREE

Gymboree Play and Music sessions are all about amalgamating fun with learning. The sessions incorporate various hands-on theme based activities for children to develop their hand-eye coordination, fine motor skills, gross motor skills, spatial and bodily-kinesthetic skills.



## FAMILY SUPPORT GROUP SESSION – OCTOBER

Ms. Nausheen Gul, Occupational Therapist from Milestones Charitable Trust, led a discussion on the “Importance of Occupational Therapy for Children with Down Syndrome”. The session was attended by 40 parents and caregiver, and highlighted some of the strategies they could implement to enhance their children’s fine motor skills.

## KDSP BEACH RETREAT

Since Down Syndrome Awareness Month is celebrated in October, KDSP held a fun-filled beach retreat for over a 100 individuals with Down syndrome and their families on October 29, 2017. The inclusive retreat featured fun beach games and delicious food for adults and children alike.



Coming together is a beginning;  
Keeping together is progress;  
Working together is success.

- Henry Ford



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