

# 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

Another year has gone by which was characterized by significant achievements, while a lot was learnt in pursuit of making KDSP more efficient and an organization with greater outreach. New initiatives were taken by KDSP, some existing programs were rejuvenated while others were added afresh!

In this issue, we are pleased to share with you two articles by mothers of children with Down syndrome. How these mothers braved through all the negativity and challenges that came their way is commendable!

This issue brings to you a lot of exciting events that took place at KDSP during the last quarter. Down syndrome awareness sessions at several educational institutions across the city, a new addition to the program for adults and an update of the ongoing programs at KDSP are but a few of those events.

As this year draws to an end, we would like to express our gratitude to Friends of KDSP for their perennial love and support. Without them, we surely wouldn't have been able to achieve half of what we have collectively achieved hitherto. Thank you! Together, we would continue to serve individuals with Down syndrome and their families much better in the coming year.

Best wishes,  
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**

# SPEAK OUT

## *I have hope for my son with Down syndrome*

Eight years ago, I was blessed with a son, Qeis; and about twenty minutes later, the paediatrician disclosed that the baby had Down syndrome. I continue to find it impossible to describe how I felt upon hearing the news - it was immeasurable to anything I had ever felt in my life.

After about three to four months, I slowly began to get a grip on reality and became eager to know what the future would look like for my child. And so, I began to research on adults with Down syndrome. That's when I discovered Pablo Penuda- a university graduate with Down syndrome! Now that was something 'possible' for Qeis as well. I was determined to find more hopeful stories as they gave me optimism that I needed to put before the other frightening possibilities.

Over the next few years, I carried on to archive all that I found, and with my skills as a graphic designer, I then designed a book titled 'Hope'. Hope is a compilation of true stories with images of children, teens and adults with Down syndrome. I was so eager to share the hope I raised Qeis with, because he grew up to be nothing like what he was projected to be!

It is crucial for all families to get an alternate view. It is this alternate view that I am here to share with you through this newsletter. More so, in order to truly 'accept' individuals with Down syndrome, our societies also need to be presented with this alternate view.

During the past 8 and a half years, I have raised Qeis with full determination- challenging him to harness his true potential. He attends year 3, in a mainstream primary school, with his brother. Honestly, my faith in humanity is now established, after observing the kindness, the innocence, the generosity in the children of our country. All his classmates are like his little guardian angels. Having the chance to witness that level of acceptance in his peers gave me hope.

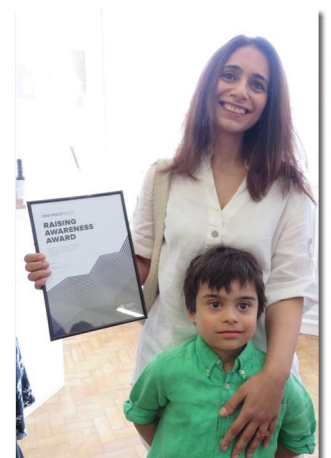
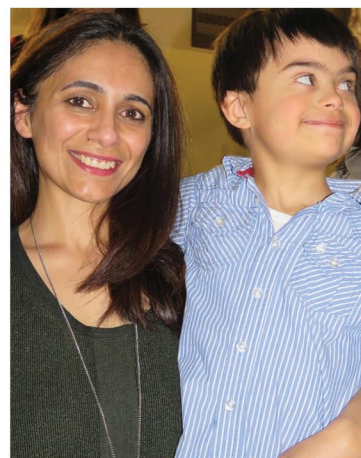
They make no judgement of him –something we need to learn from our children about tolerance and acceptance!

We bring all lives into this world with optimism. Lives with Down syndrome are just a different genetic composition. Who are we to decide that they are worth any less in comparison to others? As fellow humans, we must give them the same acceptance, tolerance and respect, as we desire for ourselves. It's pretty simple; we must stop thinking less of them. A mother of a little girl with Down syndrome put it perfectly in one of her articles, "It is not OK to discriminate against people based on age, race, religion, sexual orientation, etc., so why do some people think it's OK to discriminate based on someone's developmental state?"

My book, **Hope** is now available for purchase on Amazon Kindle, and can be downloaded on any digital device. It's a visual treat, so I suggest a large screened device. <https://www.amazon.co.uk/Hope-Tania-Khan-ebook/dp/B01LYNCUNE>

Follow me on Twitter [@SharingMyHope](https://twitter.com/SharingMyHope) and on Facebook at '[Hope-Changing perspectives](https://www.facebook.com/Hope-Changing-perspectives/)', to know more about ordering printed copies of Hope.

*Tania Naima Khan, Mother of Qeis.*



# SPEAK OUT

## My Experience

I am a mother of a beautiful daughter with Down syndrome. I conceived after 7 months of my marriage and my husband and I were both so happy. I was praying to Allah for a baby girl so I could name her Fatima. I was glad that my routine check-ups and ultrasounds went well. I soon got to know that I was to give birth to a baby girl. I was so happy and excited that my prayers were going to be fulfilled!

On 6th December 2015, I had my beautiful baby girl Fatima in my hands. My husband and I were so ecstatic I can't even begin to express our feelings in words. Then the doctor called us and told us that our baby was different from typically developing babies. I couldn't understand what the doctor was talking about. My baby looked fine to me and there seemed to be nothing wrong with her. We left the hospital and took her home. I was so worried about what was wrong with my daughter. Why did the doctor say what he did? We went to other hospitals for her checkups but the doctors over there too had the same prognosis to offer.

Then we got her test conducted from NICH, and after one month we received a report that formally declared that my daughter had Down syndrome.

I didn't know what to do. Why me? Why my daughter? What was I to do now? I was so worried. I cried a lot and was completely lost. It took a lot of time and effort for me to accept that my daughter had Down syndrome. At least 5 months later, I managed to control my emotions and accept the reality as it was. After quite some research, I came to know what I had to do; I started her therapies when she was 6 months old and gradually she started to show a definite improvement.

Now my baby is a year old and has started sitting MashaAllah. She has started recognizing faces as well. I thank Allah so much for giving me a beautiful and precious daughter like Fatima and I know when she will grow up she will be able to do everything like other people in the world.

***Faiza Ansari, Mother of Fatima.***

## IN FOCUS

### Argentine woman becomes first nursery teacher with Down syndrome

Noelia Garella- labelled a 'monster' and rejected from a nursery as a child, now has her own class of toddlers. She is the first person with Down syndrome in Argentina to work as a pre-school teacher and one of the very few in the world.

Despite opposition from parents and people in position of responsibility, Garella stuck to her passion. "I want them to read and listen, because in society people have to listen to one another", Garella said about the kids. Teachers, parents and the city's mayor decided there was no reason she couldn't teach and so Garella continues spreading joy and being an inspiration.

Source: [www.independent.co.uk](http://www.independent.co.uk)



# IN FOCUS

## Farah Vohra wins swimming championship

KDSP would like to congratulate Farah Vohra for winning a gold medal in exclusive relay race in the Sindh Women Swimming Championship held at Karachi Gymkhana Club on Sunday, October 30, 2016. Farah has been part of Special Olympics Pakistan for more than 10 years. Previously, she represented Pakistan in the Special Olympics World Games in Athens 2011 and was selected as a torch-bearer for the Asia Pacific region. You have made us all proud, Farah! More power to you.



## Volunteer Spotlight

My name is Hamza Hasan and I'm a student of eighth grade. I have had a great experience with KDSP thus far. I got to know about this organization from my sister who earlier had been a volunteer at KDSP. I've been volunteering for KDSP since a year now.

I have volunteered for The KDSP World Down Syndrome Day Carnival, the Story-Time Session, the Candy Club Sessions and the Family Support Group Sessions. I had a great time interacting with the children as well as the KDSP team. It was a great experience volunteering for KDSP as they have a great mission.

# ACTIVITIES AT KDSP

## Family Support Group Session – October

The 22st Family Support Group Session was held on October 15, 2016 on the topic, "Stress Management for Families of Individuals with Down Syndrome". The session was led by Dr. Shehla Alvi, Associate Professor and the Head of Psychiatry Department at United Medical and Dental College. Dr. Alvi spoke about the importance of acknowledging, as well as seeking help for the increased stress which some families and care-givers experience while raising a child with Down syndrome. The session served as a form of catharsis for many parents who, otherwise, do not get an opportunity to talk about and relieve their stress.



## Arts and Crafts for Adults – October

In October, the arts and crafts participants crafted more animal keychains and stuffed toys. They made stuffed toy ducks and stuffed toy ginger bread men.

## Down Syndrome Awareness Campaign

October was recognized as Down Syndrome Awareness Month and KDSP conducted Down Syndrome Awareness sessions in various educational institutions across Karachi. The aim was to promote inclusion by virtue of raising awareness about Down syndrome. Some of the educational institutions that wholeheartedly participated include, The Lyceum School, IBA, Beaconhouse, The Anchorage School, The AMI School and Haque Academy. Interested students also signed up for the KDSP's Volunteer Program.



# ACTIVITIES AT KDSP

## Family Support Group Session – November

On November 26, 2016 Dr. Mumtaz Jamshed led a discussion on “Relevance of ENT for Individuals with Down Syndrome” Dr. Jamshed is an ENT surgeon at AKUH. During the session he emphasized upon the common ENT issues faced by individuals with Down syndrome and the need to timely address those issues.



## Candy Club Sessions

In the previous quarter, the Candy Club sessions took a new turn by introducing pottery making to the participants. The children had a wonderful time experimenting with clay and using their imagination to mould it into different shapes and figures.

## Arts and Crafts for Adults – November

Having created enough stuffed toys and keychains to last for a long time, in November, the participants made decorative ceramic bowls. They shaped the clay into bowls of different shapes and sizes according to their preferences, and once dried, they painted these bowls with different colours and designs.



# ACTIVITIES AT KDSP

## Yoga for Adults

KDSP introduced a new program for adults with Down syndrome which began on November 19, 2016. A professional yoga instructor from Special Olympics Pakistan conducts these classes every Saturday afternoon in which the participants had a fun time relaxing and stretching their muscles.



## Arts and Crafts for Adults – December

A weaving module was introduced in the weekly arts and crafts classes for adults. The participants were taught how to fasten threads on a weaving table and the following sessions revolved around making the participants familiar with weaving equipment and tools.

## Family Support Group Session – December

The 24th Family Support Group Session was held on December 17, 2016 on the topic, “Down Syndrome: A Team Approach”. The discussion was led by Dr. Salman Kirmani, Associate Professor and head of pediatrics department at AKUH. The session was attended by 35 parents and care-givers.



# HEALTH & DEVELOPMENT

Behavioral issues are common amongst all children, however, they tend to be more common amongst children with Down syndrome. One of the most common perceptions regarding behavioral issues and misbehavior is that a child misbehaves because they are mean-spirited or stubborn. This is not the case for children with Down syndrome. One of the primary reasons that children with Down syndrome face behavioral issues is because they have difficulties in expressing themselves. When they are unable to freely express themselves, they become frustrated and their frustration manifests in the form of behavioral issues.

Misbehavior, especially one that is verbally or physically abusive to others, should not be ignored and should instead be dealt with appropriately. Screaming or lashing out against the child is highly unlikely to yield any positive results. Allow a child to calm down or cool off after a misdemeanor or calmly remove them from a volatile situation. After this, the child can be told about the consequence for the negative behavior in a concise and simple manner. For children who have language difficulties, long verbal lectures or interrogations regarding the misdemeanor will leave the child confused and even more frustrated. Calmly tell the child that they have broken a rule and the consequences which follow each time they break the rule.

Many children with Down syndrome are very social. They often love to receive attention, even if it is negative. If a behavior is not unsafe, try ignoring it and give no feedback. Sometimes this is enough to get rid of a behavior. Also, since they are social learners, modeling the best behavior around them is crucial in inspiring them to repeat the same behavior in other social contexts. The basic principle for fostering positive behavior is to provide praise and encouragement for appropriate pro-social behaviors. Children with Down syndrome often

respond to visuals better than being told what to do. Make a chart with pictures of what you'd like your child to do and put it up where he or she can see it, maybe on the bedroom's wall or the refrigerator. Each time a child demonstrates good behavior listed in the chart, reinforce the behavior with a small reward – such as extra play time, a small bar of chocolate, a hug or a praise. Gradually, through repetition, children will be able to draw a connection between good behavior and positive reinforcement.

A child's maladaptive behavior speaks volumes about their unmet needs and accompanying frustration. Remembering that your child is trying to communicate something, can make it easier to deal with difficult behavior. Like all children, the social development and behavior of children with Down syndrome gradually improves with time and consistent effort on part of both parents as well as the child.

**Source:** [www.ndss.org](http://www.ndss.org), [www.down-syndrome.org](http://www.down-syndrome.org) and [www.dsagsl.org](http://www.dsagsl.org)



Karachi Down Syndrome Program

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