

# 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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## IN THIS ISSUE

Editorial	Page 1
Speak Out	Page 2
KDSP Carnival 2017	Page 3
Launch of Down syndrome Clinic at AKU	Page 4
Activities at KDSP	Page 5
KDSP's Music Video	Page 7

## EDITORIAL

Welcome to a new issue of your favorite newsletter, A Little Extra! It has been a busy time at KDSP since our last communication, and we are thrilled to share it with our supporters.

The KDSP team would like to extend a big thank-you to the wonderful friends and family who have helped us to make World Down Syndrome Day (WDSY 2017) such a success - we couldn't have done it without your support. This year, our reach has been bigger and bolder than ever before and it's been an exhilarating ride.

This issue will give you a detailed round-up of KDSP's World Down Syndrome Day related activities. We have been very lucky to have had our Goodwill Ambassadors take the cause forward!

If you haven't done so yet, consider sharing YOUR KDSP story! Remember, by doing so, not only do you contribute to the development of a community that cherishes and appreciates our friends and family members with Down syndrome but you also help to do away with stereotypes associated with the extra, magical 21st chromosome. And of course - it's always nice to see your own name in print! Please write in to us anytime at [publications@kdsp.org.pk](mailto:publications@kdsp.org.pk) with your comments or queries. We look forward to hearing from you!

Best wishes and happy reading,  
Team 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

My sister Saamia recently turned 18 in January & goes to SCEI. Here are a few stories of our little Saamia who is the the light of our life!

Saamia, our ray of hope and sunshine. She was born into this world in the winter of 1999 when all of us siblings were too young to realize that she was special. And indeed she was! Special as she always bore a beautiful smile on her face. Special as she always needed our help hence was totally inseparable. And mostly special as she was dearly loved by everyone including her 3 year old sister who unlike most children wasn't at all jealous of why everyone paid more attention to Saamia than her.

Saamia initially could not walk, so her crawling movement restricted mobility and exploration, but little did we know that she was quite sharp in observing others. She watched her older sister climb on a cupboard and access all the toys, so she cleverly copied the movement – unfortunately it led to a fall and she was rushed to the hospital. That wasn't the only time we were struck with the horror of losing her. When she was only 6 months old, the doctors diagnosed her with water in her lungs and she was hospitalized for quite some time. Injections punctured her all over, from her skull to her tiny little feet. She bravely endured it all, while we only prayed and wept.

Saamia's beautiful smile always brings blessings to our occasions. We always encourage her participation in any event large or small: from birthday parties to small family gatherings or dinners. She is always the first one to get ready and the most excited! We embrace her as the beautiful person she is.

She has a heart of gold and is extremely sensitive as well. She always knows when one of us is upset and she will come wipe away tears tears and literally take all the worries away. She always appreciates surroundings, and can make my day simply by saying "AHAAA" or "Wow" if she sees me wearing a beautiful outfit. Her favorite hobby is arranging things and my oh my, what an immaculate organizer is she! From setting the dinner table to finishing every last bit on her plate, she possesses manners that every parent would want to inculcate in their own little ones.

She is our biggest blessing from Allah- extremely obedient and organized, and greeting everyone with a handshake or a hug and loves to share food and toys.

## Saba Javed, Sister of Saamia









# Launch of Pakistan's first Down syndrome Clinic at AKUH

KDSP teamed up with The Aga Khan University Hospital (AKUH) for a revolutionary 'one stop health solution' to facilitate parents bringing their child with Down syndrome, to see different specialists at AKUH, in one clinic. Up until now, parents would struggle to find the appropriately trained specialists to treat separate health challenges faced by their children with Down syndrome.

A team of internationally trained and experienced child specialists practicing at the AKUH, led by Dr. Salman Kirmani and Dr. Babar Hasan, joined forces with the world renowned Down syndrome expert, Dr. Brian G. Skotko, as well as the founder of KSDP, Mr. Ali Allawala, and staff, to share best clinical practices for Down syndrome management at a session held in the AKU auditorium, on 9th April 2017. This session was attended by medical professionals and students, parents & families of people with Down syndrome as well as supporters of the cause.

Speaking about the launch, Dr. Salman commented,

"The new Down syndrome Clinic at the AKUH became possible because of conversations with KDSP. We have been informally working with KDSP for 3 years, and now spreading the word so the medical community is aware and can guide these individuals to the Down syndrome clinics where all their healthcare needs can be met."

While speaking live from Massachusetts General Hospital, Boston, on this occasion of the first Down syndrome Clinic launch in Pakistan, Dr. Brian Skotko said,

"According to a research study by the American School of Medical Genetics about self-perceptions from people with Down syndrome, about 99% expressed being happy with their lives", and even though it is challenge and adjustment for families, "99% of the parents, and 97% of the siblings, love their child/sibling with Down syndrome."

**The full recording of the event can be viewed on KDSP's YouTube channel.**



# ACTIVITIES AT KDSP

## Pakistan Day Event

To commemorate the 77th anniversary of the Lahore Resolution passed on 23 March 1940, KDSP & our Goodwill Ambassador Ali Hamza observed Pakistan Day with great fervor at Dolmen Mall Clifton. Products made by our adult Arts & Crafts class were on display as merchandise. Ali Hamza performed a rocked out version of the National Anthem, as well as our KDSP Anthem – Aao Humary Saath Chalo. We're truly blessed to be surrounded by people who share our vision of an inclusive society!



## Workshop on Inclusive Education

This is the second year of KDSP's collaboration with Down Syndrome Education International (DSEI) to pioneer a program on inclusive education. Saira Ibrahim, Nasira Faiz and Farzeen Ali Allawala conducted a session on awareness and inclusion, followed by Professor Sue Buckley (via Skype). Over 25 teachers from different schools in Karachi participated and we look forward to a productive academic year ahead!



## Goodwill Ambassadors

KDSP's biggest strength has always been the families and people who support us. Since our inception, we have relied on this network and it has taken us to heights we never dreamed of! Now, we have the privilege of having special KDSP Goodwill Ambassadors, who are active members of society and will help us to spread our message even further.

We are honoured to introduce Ali Hamza, as our first Goodwill Ambassador and the voice of our favourite song, Aao Humaray Saath Chalo. Hasan Rizvi is our second Goodwill Ambassador for 2017!



# ACTIVITIES AT KDSP

## Arts & Crafts classes for Adults

A glimpse of our weekly Arts and Crafts classes for adults aged 15 and older. These classes are taught by the lovely Mrs. Mahtab Pirzada and Mr Usaama Qadri. The participants create beautiful handi-crafts that have been sold at our Annual Carnival and continue to be displayed as merchandise throughout different exhibitions in Karachi.



## Yoga Classes

A peek into our weekly Yoga class! This class is conducted by the wonderful Azmat, who has graciously volunteered her time. It is a fantastic way to take a break and let tired muscles relax. Azmat is a professional yoga instructor from Special Olympics Pakistan and she conducts these classes every Saturday afternoon in which the participants have fun time relaxing and stretching their muscles.



## Morning Shows

Ali Allawala & Ali Hamza appeared on Good Morning Aaj to talk about raising awareness about Down syndrome: as Aaj Tv has enormous reach, sharing an important story can help inspire others and illustrate once more how people with Down syndrome belong in our society.



# KDSP's Music Video

This year, KDSP teamed up with Ali Hamza, our first Goodwill Ambassador, to release the music video "Aao Humaray Saath Chalo" – a song sung by Ali Hamza and written by Zehra Nigah. The music video has been directed by Amaan Ahmed and styling has been done by Ehtesham Ansari. The cause is being enthusiastically supported by several celebrities namely Bushra Ansari, Sarwat Gilani, Javed Sheikh, Ahsan Khan, Momal Sheikh, Anoushey Ashraf, and Sheema Kirmani, all who are featured in the video.





Karachi Down Syndrome Program

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

## **Karachi Down Syndrome Program**

Suite 102, First Floor, Jason Trade Centre

Main Shahra-e-Faisal, Karachi.

Phone: (9221) 34315377 or (9221) 34385377

Email: [info@kdsp.org.pk](mailto:info@kdsp.org.pk)

Website: [www.kdsp.org.pk](http://www.kdsp.org.pk)

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