

# A LITTLE EXTRA

Karachi Down Syndrome Program's Quarterly Newsletter

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



SUMMER 2015 EDITION

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## Editorial

Welcome to the first ever KDSP Newsletter! The last few months at KDSP have been very exciting! We completed a successful awareness campaign on the occasion of World Down Syndrome Day 2015 which culminated with the fun-filled KDSP Carnival on March 22<sup>nd</sup>. Details of our 2015 campaign and more are included in this first edition of our newsletter.

At KDSP, we want to work towards changing society's perception of Down syndrome and how people with Down syndrome can often accomplish more than we think they can. This effort for change however, will not be possible without the constant guidance and advice from the families and supporters of our friends with Down syndrome. This newsletter, and all the subsequent ones to follow, are just a small part of that effort. Nonetheless, we urge you to provide us with feedback on how we can improve and what sort of information you would like to find in our quarterly publications. Please feel free to write in to us at [publications@kdsp.org.pk](mailto:publications@kdsp.org.pk) with your input and queries about this newsletter or our events and programs. It would be great to hear from you!

Best wishes,  
Team at KDSP



Karachi Down Syndrome Program

## 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.

# CELEBRATING WORLD DOWN SYNDROME DAY 2015



## KDSP Carnival 2015

On the occasion of World Down Syndrome Day 2015, KDSP hosted a Carnival for everyone!

On Sunday, the 22<sup>nd</sup> of March 2015, the Karachi Down Syndrome Program hosted a carnival at the Beach Luxury Hotel with the aim of celebrating World Down Syndrome Day and to show that an inclusive society is truly possible. Families of people with Down syndrome, their friends, excited volunteers and celebrities and other supporters of KDSP came together for an evening full of fun, games, dance, delicious food – and best of all, the biggest smiles!

From 4pm through 8pm, people danced, sang, played games at the games stalls



The children had fun hitting the sponge on the brave volunteers, knocking over the tin can alley, and riding the train!

fabulous moves than on the stage! Our friends with Down syndrome had the most fantastic time showing off their dance moves and grooving to the beat!

KDSP is extremely grateful to all the Carnival sponsors who made the event possible. Their generosity brought together people from all backgrounds and all abilities and showed that a tolerant and inclusive society is indeed possible!

## Recognize the possAbilities!

and won all our winner gifts so fast that most of the KDSP team was having trouble keeping up the supply of the winner goody bags! After everyone was exhausted from playing and having fun, the food area was there to provide them with the energy they needed; juices, drinks, doughnuts, pizza, brownies and cupcakes, chaat, gol gappas and ice cream!

For the artsy people, there was the paint-your-own-t-shirt stall as well as an art corner. It was a fun win-win for all! Some of the most popular stalls at the Carnival was the photo-booth and the Raffle and Lucky draw. One lucky winner walked away with two tickets to Dubai!

The most happening place at the Carnival though was the centre-stage where the dance competitions were underway! Never have we seen more



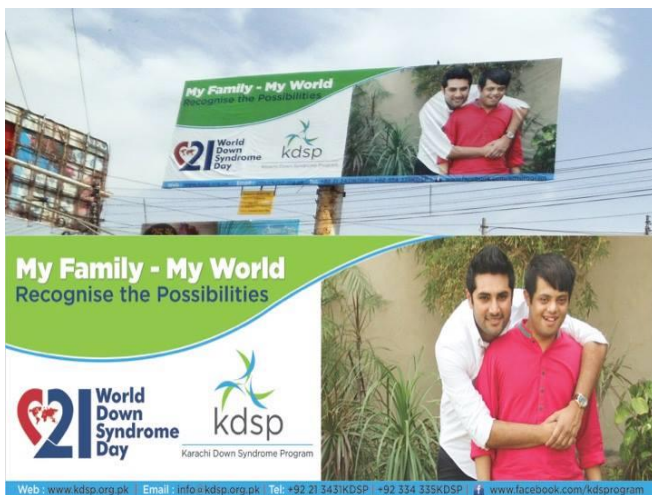
We look forward to celebrating World Down Syndrome Day next year with the same fervor, enthusiasm and support from everyone. By spreading awareness together, we can help shatter stereotypes and celebrate all individuals regardless of their abilities.



# WDSD 2015 Campaign Highlights

## 21 Billboards for the 21<sup>st</sup> chromosome!

March 21, 2015 marked the 10<sup>th</sup> anniversary of the World Down Syndrome Day. KDSP celebrated this day with the aim of creating awareness about Down syndrome and making our society tolerant towards, and inclusive of our friends with Down syndrome.

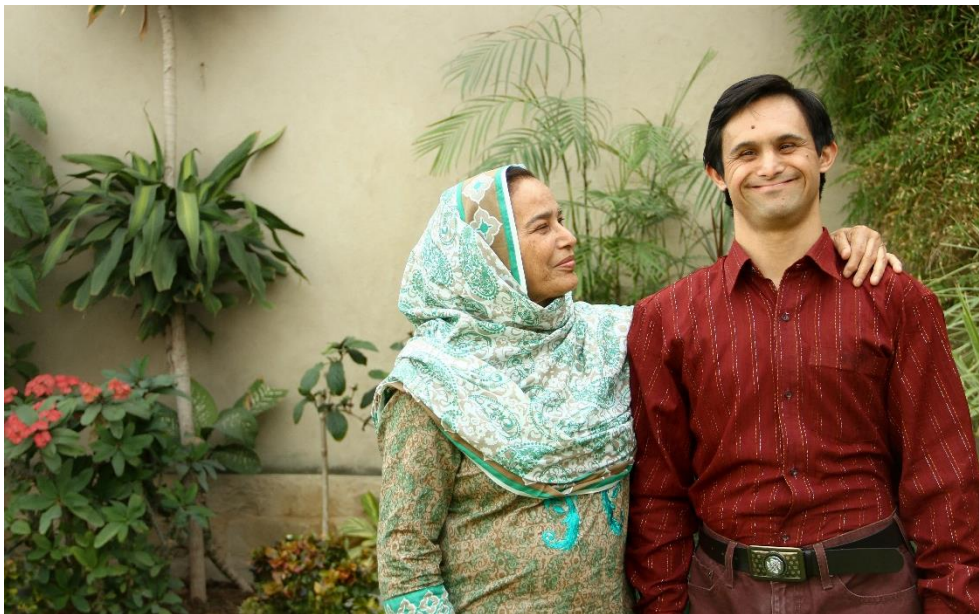


For this occasion, KDSP put up 21 billboards all around the major areas of Karachi to create awareness about Down syndrome and celebrating the role the families in the lives of people with Down syndrome. 21 billboards were set up around Karachi to recognize the 21<sup>st</sup> chromosome.

## 4<sup>th</sup> UN Conference on Down Syndrome

On March 20, 2015, representatives from KDSP attended the 4th World Down Syndrome Day Conference at the UN Headquarters, New York. The theme for the conference was *"My Opportunities, My Choices' – Enjoying Full and Equal Rights and the Role of Families"* and this theme was also incorporated into KDSP's entire campaign. Our delegates returned with beneficial insights as to how to make our society more inclusive for individuals with Down Syndrome.





“My Opportunities,  
My Choices –  
Enjoying Full & Equal  
Rights and the Role of  
Families”

Theme for WDS  
2015

## Raising awareness with KDSP Video 2015

KDSP developed a short video based on the theme of World Down Syndrome Day 2015, highlighting the positive role of family members in the life of a person with Down syndrome. The shorter version of the video was used to promote public awareness about Down syndrome by running prior to the start of every film at the Atrium Cinemas, Karachi on the 20<sup>th</sup> and 21<sup>st</sup> of March 2015.

The video also aired several times all week leading up to World Down Syndrome Day on major news channels including Aaj TV, Samaa TV, Geo News, Dawn News, etc. Awareness was also raised by posting the video on social media i.e. Facebook, Youtube and Daily Motion and reached more than 500,000 views collectively. Representatives from KDSP also appeared

live on the morning shows of major mainstream channels, including Aaj TV, Health TV, Samaa TV, Dawn News, etc. on the days leading up to WDS 2015. The KDSP video was aired during these morning shows as well. Aaj TV in particular, hosted representatives of KDSP on its morning shows on the 20<sup>th</sup> and 21<sup>st</sup> of March.



## Awareness through print advertisement

A print ad which relayed the significance of World Down Syndrome Day was prepared and printed in two different magazines, one of which was a newsletter for the Karachi Grammar School and its alumni, and the other being SellOut! – a popular home marketing magazine.

### MY FAMILY - MY WORLD - RECOGNISE THE POSSIBILITIES

In these photographs you'll find people who were born with an extra copy of chromosome 21, all of them surrounded by their fathers, mothers, sisters and brothers.

The condition known as Down syndrome can lead to varying degrees of physical and intellectual disability but family members can play a pivotal role in empowering them to lead full and productive lives and in promoting their equal status in society. By providing the right support and with early intervention, families can help people with Down syndrome lead independent lives, be accepted and included as valued, equal and participating members of their communities.

21<sup>st</sup> March is a global awareness day officially observed by the United Nations to raise awareness of what Down syndrome is, what it means to have Down syndrome and how people with Down syndrome can play a vital role in our lives and societies. Join the cause to advocate for the rights, inclusion and well-being of people with Down syndrome.



Karachi Down Syndrome Program  
\*A company's 1st (up) under section 42 of the Companies Ordinance, 1994.\*

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design: dsnp-3418118

# ACTIVITIES AT KDSP! APRIL – JUNE 2015

## Trip to KidzDunya

On May 12, 2015 children between the ages 4-12 visited KidzDunya – an indoor amusement park in Karachi. This exhilarating trip provided the children a chance to engage in numerous fun filled activities and games. A role playing game saw the children taking on the role of policemen and catching thieves, and learning about police responsibilities. The children also dressed up as firefighters and role-played extinguishing fire. The children unleashed their artistic creativity in the ice-cream designing and painting activities, where designed ice-creams according to their own taste, and took pride in eating their own creations later.



## Art and crafts classes for adults



Who doesn't love art and crafts? Be it kids or adults, art and crafts is that one activity that appeals to all alike! Weekly art and crafts sessions for adults were held at KDSP by Mrs. Mahtab Pirzada from April to June. The initial class focused on teaching our friends with Down syndrome how to hold the needle steadily, and as the classes progressed they were taught different stitching styles along with applique designing. Everyone then came up with their own projects incorporating all that they learnt in these classes. One of the main aims of these classes was that the skills inculcated in these activities can also prove to be fruitful if the students wish to make handicrafts and start up their own, independent businesses in the future.

## Clay class for children

Children had a busy time modelling, squashing, rolling and pounding during a Clay therapy session held on May 30, 2015 by Abeer Asim from Mudpie Ceramic Art Studio. The children let their imaginations run wild by making animals, aliens and various other characters out of clay, and then concocting a story involving those characters. Parents too seemed to have as much fun as their kids as they helped their children in creating characters and stories. Modelling clay helped enhance fine motor skills, and coming up with imaginative stories reinforced the children's critical thinking.



## Family Support Group Session (April) – Common Infections in DS



KDSP's monthly Family Support Group Session for the month of April was conducted by Dr. Fatima Mir on the topic of "Common Infections in Children with Down Syndrome and Related Vaccinations" on 18th April at the KDSP office. Dr. Fatima Mir is a Faculty Member of the AKUH Department of Pediatrics and Child Health. This very informative session was attended by 26 parents and family members. Dr. Fatima Mir explained in detail the most common infections to which children with DS are susceptible to, the symptoms as well as preventive vaccines.

## Family Support Group Session (May) – Speech Therapy & DS

On May 16th, Ms. Amna Siddiqui who is an Assistant Professor, Audiologist and Speech Language Therapist as well as the Principal of College of Speech Language & Hearing Sciences, Ziauddin University conducted a Family Support Group Session on "Speech Therapy & Related Issues". This session was targeted towards parents and caregivers of younger children and Ms. Siddiqui relayed valuable information relating to the importance of early speech intervention for children who have Down syndrome. The session was attended by 61 parents and family members.



## Family Support Group Session (June) – Occupational Therapy



June's Family Support Group Session was held on June 13<sup>th</sup>, 2015 by Najma Adam who is an occupational therapist at the South City Hospital, Karachi. The topic for this session was Occupational Therapy where parents were briefed about the importance of introducing occupational therapy as early intervention for children with Down syndrome, and its related benefits. The session was attended by 25 parents and caregivers.

# Health & Development

## Sleep Apnea and Down Syndrome

**Sleep apnea** is a sleep disorder in which breathing repeatedly stops and starts. There are two main types of sleep apnea:

- Obstructive sleep apnea, the more common form that occurs when throat muscles relax
- Central sleep apnea, which occurs when your brain doesn't send proper signals to the muscles that control breathing

There is a 50-100% incidence of obstructive sleep apnea in individuals with Down Syndrome with anatomy being the main reason of this higher incidence. Some factors include: central apnea, low muscle tone in the mouth and upper airway, narrowed air passages in the midface and throat, a relatively large tongue, and enlargement of adenoid and tonsillar tissues. Increased upper airway infections

and nasal secretions and a higher incidence of obesity further contribute to this.

Sleep disordered breathing has been shown to affect cognitive abilities, behavior, growth rate and in some cases, more serious consequences of pulmonary hypertension (abnormally high blood pressure in the arteries of the lungs) and heart failure.

Symptoms that are suggestive of sleep abnormalities include: restless sleep, snoring, gasping noises, heavy breathing, apneic pauses, frequent waking during the night, trouble getting out of bed, daytime sleepiness and excessive napping. Sleep apnea can also cause behavioral changes, including symptoms of irritability, poor concentration and impaired attention.

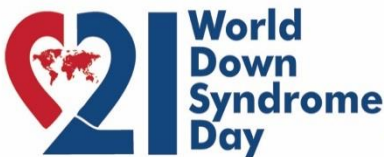


Consult your child's doctor or a specialist if you think your child may have symptoms of sleep apnea. Usually an overnight sleep study is performed to determine any unusual sleep patterns and to monitor oxygen intake levels. Surgical removal of the adenoids and tonsils may be prescribed to treat the symptoms of obstructive sleep apnea.

Source: National Down Syndrome Society, [mayoclinic.org](http://mayoclinic.org)

## My Family - My World

### Recognise the Possibilities



**World  
Down  
Syndrome  
Day**



**kdsp**

Karachi Down Syndrome Program



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One of our billboard designs from our World Down Syndrome Day 2015 Campaign

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