





## **ANNUAL REPORT**

2015-2016

Karachi Down Syndrome Program

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



















Recognise the Possibilities

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## Introduction

### Mission

The mission of the Karachi Down Syndrome Program is to be recognized as the foremost organization in Karachi for information, networking, and advocacy for and about Down syndrome, by people with Down syndrome and their families, educators, health care professionals, and the community-at-large.

#### Vision

The Karachi Down Syndrome Program envisions a world in which all people with Down syndrome are accepted, included and are given the opportunity to enhance their quality of life, realize their life aspirations and become valued members of welcoming communities.

### **Purposes**

As the primary advocate of people with Down syndrome in Karachi, KDSP intends to conduct activities such as:

- Facilitate mainstream schooling for children with Down syndrome
- Educating parents through theme based meetings and events.
- Providing early intervention and support for children with Down syndrome.
- Holding events in which people with Down syndrome can participate in and exhibit their strengths in order to create an inclusive society.

## Introduction

#### **Board of Directors**

KDSP is guided by the leadership of a competent and dedicated group of parents and professionals.

Ali Allawala

Chairman and CEO

Dr. Zehra Habib

Director – Early Intervention

Muhammad Ali Siddiqui

Director - Family Support Group

Fauzia Hussain

Director – Education & Training

Nasira Faiz

Director – Education & Training

Prof. Jamal Ara

Director - Health Care

Rashida Faheem

Director – Events and Program

Shakila Iqbal Allawala

Director – Fund Raising

Seema Zuberi

Director – Media & Communication



# **Director's Message**

With the continuing generosity of our supporters, KDSP has been able to achieve some exciting milestones this past year.

March 21st is celebrated globally as World Down Syndrome Day. KDSP joined the celebrations for the second year in a row by organizing a Carnival at the Beach Luxury Hotel. Through this annual event, KDSP aims not only for individuals with Down syndrome to have a fantastic afternoon filled with fun and games, but also to promote inclusion and for the larger society to realize that individuals with Down syndrome are more alike than different.

Also as part of our annual awareness campaign revolving around World Down Syndrome Day 2016, KDSP launched an extensive social media campaign involving an awareness video as well as endorsements by 21 celebrities. KDSP also carried out an outdoor media campaign, and launched a children's book that emphasizes acceptance and inclusion of people with Down syndrome.

One of the most significant achievements for KDSP this year has been the launch of the Project for Inclusive Education. Advocating for the benefits of inclusive education for children with Down syndrome has enabled KDSP to partner with mainstream schools and promote an effective learning environment for all children, those with extra needs learning challenges as well as those who are typically developing. For this purpose, KDSP has partnered with Down Syndrome Education International (DSEI), to arrange a series of workshops where trainers from the UK come and train teachers locally to equip them in handling the needs of children with Down syndrome. KDSP hopes that the launch of this project will be the beginning of many positive changes in the lives of children with Down syndrome living in Karachi, by providing them with a very real opportunity to have access to quality education.

# **Director's Message**

During the year, KDSP has continued to grow its in-house early intervention therapy clinics and we now run clinics for all three disciplines i.e. Occupational, Physical and Speech therapy. Our dedicated and qualified therapists continue to work hard every day to ensure younger children with Down syndrome continue to get the much needed and timely intervention for their optimum physical and intellectual development.

In order to create awareness amongst the masses, KDSP's publications team introduced the circulation of quarterly newsletters highlighting the work KDSP is doing along with the achievements of individuals with Down syndrome for the larger society.

KDSP continued to hold its monthly Family Support Group meetings aimed to educate our Family Network and allow caregivers to connect with each other and develop a support system for themselves. This year, renowned speakers spoke on areas such as the Importance of inclusive education, dental care, cardiac health, ENT, and concerns regarding ophthalmology in individuals with Down syndrome.

We are once again very thankful to our partners and supporters. Without their generosity and encouragement, we would not be able to pursue our objectives the way we do. Above all, we would like to thank our champions with Down syndrome for giving us the pleasure to represent them and work to promote their interests. Because of them, our work is joyful every day!

Ali Allawala – Chief Executive, Karachi Down Syndrome Program.





### **Family Support Services**

KDSP firmly believes that the key to enabling individuals with Down syndrome is to ensure that their parents and caregivers have the required support and information. This allows them to be effective advocates for their family members. Family Support Group (FSG) meetings play an integral role in providing a platform where the challenges of having a person with Down syndrome in the family can be addressed and resolved. These regular meetings are also a source of deep and much-needed emotional support for families in a society that still has a long way to go in being truly inclusive. Over the past year, KDSP has successfully hosted 10 FSGs on themes including education, physical health, emotional wellbeing and pediatric rehabilitation. Each session caters to 35-40 parents and caregivers. Following are some of the past FSG topics and presenters:

- Eye Care for Children with Down Syndrome by Dr. Irfan Jeeva (Assistant Professor of Opthalmology, Aga Khan University Hospital)
- Dental Care in Children with Down Syndrome by Dr. Irfan Qureshi (Chief consultant at Dr. Irfan Qureshi's Team of Professionals and the Head of the Department of Prosthodontics, Sir Syed College of Medical Sciences)
- Skin Care Needs of Individuals with Down Syndrome by Dr. Saadia Tabassum (Consultant Dermatologist and Assistant Professor in the Department of Medicine, Aga Khan University Hospital)
- Cardiac Issues Faced by Individuals with Down Syndrome by Dr. Babar Hasan (Pediatric Cardiac Health Specialist at Department of Pediatrics and Child Health at Aga Khan University Hospital)
- Occupational Therapy For Children with Down Syndrome by Najma Adam (Occupational Therapist
  at the South City Hospital)
- Inclusive Education for Individuals with Down Syndrome by Dr. Kausar Waqar (Faculty Member of Human Development Department, Aga Khan University Hospital)









### **Early Intervention Program**

The first 1000 days of a life of a child with Down syndrome are known to be the most crucial for their development. Since children with Down syndrome typically face delays in development, it is highly recommended that early intervention should begin immediately after the birth of a child with Down syndrome. Early intervention refers to a comprehensive program of physical therapy, speech therapy and occupational therapy designed for a child's specific needs. These therapies usually continue from birth to 3 years of age.

Early intervention therapies are offered at KDSP by professionals with a breadth of experience and knowledge. Therapy clinics run from Tuesday to Saturday from 9 am to 5 pm. All therapies are offered at KDSP at highly subsidized rates.

KDSP began offering occupational therapy in early 2015. Currently there are 19 children benefiting from KDSP's occupational therapy services.

Physical Therapy was introduced in January 2016. Physical therapy is directly looked over by Dr. Zehra Habib, who is the only PhD in Physical Therapy in Pakistan. There are currently 33 children from the KDSP Family Network benefiting from KDSP's physical therapy services. Speech Therapy was introduced in March 2016. There are currently 10 children benefiting from the speech therapy services at KDSP.

In order to cater to the increasing demand of Early Intervention services offered, KDSP will soon expand its premises to construct well equipped therapy rooms in addition to hiring more professionals to provide high quality services to children with Down syndrome.









## **Project for Inclusive Education - Training and Placement**

After early intervention, the next step in the journey towards independent living is to ensure that a child with Down syndrome receives quality education. Education is a fundamental human right and essential for the exercise of all other human rights. It promotes individual freedom and empowerment and yields important development benefits. Providing access to education for individuals with Down syndrome is crucial to ensuring their social inclusion, and enabling them to live and work independently.

There is significant research documenting the success of inclusive education for children with Down syndrome. In an inclusive educational setting, both children with Down syndrome as well as typically developing children study together. By KDSP's definition, inclusion makes room for a person who would otherwise be excluded from a learning environment fundamental to every student's development. With this perspective in mind, KDSP launched the Project for Inclusive Education (PIE) in 2016. The aim is to partner with mainstream educational schools, provide them with best practices of inclusive education, and help these schools to successfully admit and educate children with Down syndrome while providing a conducive environment for the child's ideal personal, social and intellectual development.

KDSP has partnered with the following schools for PIE:

- 1. CornerStones School
- 2. The Learning Tree
- 3. Meezan Academy
- 4. The AMI School
- 5. CAS

In order to successfully achieve its aim, KDSP collaborated with Down Syndrome Education International, UK to pioneer the PIE. In April 2016, Rebecca Baxter, a leading expert in inclusive education for children with Down syndrome from DSEI was invited to KDSP to conduct a two day teachers' training workshop for the teachers of all partner schools. In this workshop, the teachers were taught how to develop an Inclusive Education Plan (IEP) for children with Down syndrome and were equipped with the knowledge of optimizing the academic and social learning of a child with Down syndrome in an inclusive school environment.





### **Child Enrichment Programs**

#### **DramaMama**

These sessions are conducted by Hiba Masood of DramaMama. Story Time with Drama Mama creatively interweaves books and music to create a fun filled time of laughter and learning for children with Down syndrome, their siblings and their caregivers. These sessions cater to children between 0-7 years.



### **KidzDunya**

The quarterly trips to KidzDunya offers children a chance to engage in numerous fun filled activities relating to role playing as policemen, doctors and firefighters. The trip caters to children between ages 4 and 12 years.



### Karachi American School (KAS) Sports and Arts & Crafts

Students of the KAS partnered with KDSP and launched Arts and Crafts, and Soccer Club sessions at their school premises. The modules not only promised a fun filled time for the children, but also aimed to enhance their gross motor skills, overall physical agility and cognitive capability. There were qualified trainers for both arts and crafts and soccer modules to guarantee unlimited learning. The program lasted from September 2015 to December 2015.

### **Child Enrichment Programs**

### **Workshop on Reading Skills**

Workshop on Reading Skills on aiding a child with Down syndrome how to read was conducted by Ms. Hilla Javeri on November 7, 2015. Ms. Javeri used her years of experience as a Montessori teacher to teach parents the best way to inculcate reading skills in children with Down syndrome who are as young as 1 year old.



#### **Dessert Time**

This one-day program held in October 2015 catered to children between 5 years to 12 years in which they made Oreo balls. Activities such as kneading and rolling helped improve the children's fine motor skills.



### Therapeutic Play, Arts and Clay Sessions

These sessions were conducted by Abeer Asim from Mudpie studios in May 2015 and December 2015. The sessions catered to children between 5 years to 12 years of age. Making clay figures and jewelry not only enhanced the children's fine motor skills, but also nurtured their imagination and creativity.



### **Adult Enrichment Programs**

#### **Arts and Crafts for Adults**

Weekly arts and crafts classes are conducted for adults with Down syndrome above 18 years of age. These classes are mentored by Mrs. Mahtab Pirzada, an arts and crafts expert and an entrepreneur. The beautifully crafted products by the participants were put up for sale at the KDSP World Down Syndrome Day carnival held in March 2016. The proceeds from the sales of the products were given to the participants in order to foster a sense of achievement and economic independence.













### **Programs Coming up**

#### **KDSP Summer camp**

From July 19, 2016 to August 2, 2016 in association with Candy Club to help children develop their expressive skills, musical intelligence, gross motor skills and hand-eye coordination.

### KDSP to participate in the Indie Art and Craft Show

The products of the arts and crafts participants will be exhibited at the Indie Art and Craft Show to be held on July 17, 2016 at the Royal Rodale club. The proceeds from the sale of products will be returned to the participants who made them.

### **Candy Club sessions**

Independent sessions will be conducted by Candy Club from September 2016 onwards. In these sessions, the children will participate in art based activities which revolve around science and mathematics. These exciting activities will guarantee learning and also help enhance the children's hand-eye coordination.

### **Yoga for Adults**

This program is to be launched in association with Special Olympics Pakistan (SOP) in November 2016. The professional trainer from SOP will conduct weekly Yoga classes for adults with Down syndrome.

### **Programs Coming up**

### **Young Athletes Program**

The program will be launched in collaboration with Special Olympics Pakistan (SOP) in December 2016. Special Olympics Young Athletes is a sport and play program for children between ages 2 to 7 years old. Young Athletes introduces basic sport skills, like running, kicking and throwing. Experts from SOP will train the parents of children with Down syndrome to conduct sports related activities with their children at home in order to refine their motor skills, socio-emotional skills, as well as to develop their sports readiness.

### **Collaboration with Aga Khan University Hospital**

KDSP is in the process of collaborating with AKUH in order to facilitate members registered as part of KDSP Family Network database to access medical consultation and support services being already offered at the esteemed hospital. Further, it will also facilitate mutual exchange of information, resources and expertise between KDSP and AKUH, resulting in increased awareness amongst parents and caregivers of individuals with Down syndrome.







### **Campaign Theme**

"Their smile. Your heart. Our world." The theme of the campaign revolved around the benefits of an inclusive society for today's children and tomorrow's adults.

### **Objectives:**

- To educate the masses about what Down syndrome is
- To emphasize the positive role of the families and the impact they can have on individuals with Down syndrome
- To emphasize the positive role of the larger community in ensuring an inclusive society for individuals with Down syndrome

#### **Activities:**

- Developed a short video promo which highlighted the importance of love and care for a child with Down syndrome in their first 1000 days. The video was shared on the KDSP website, Facebook page and on Youtube and reached more than 20,000 views collectively.
- Developed an outdoor media campaign. The billboards portrayed individuals with Down syndrome
  with their siblings to encourage the audience to practice inclusion and to love and accept people with
  Down Syndrome for who they are. Billboards of sizes 60x20 and 45x15 and 6x12 were placed in major
  areas of the city including Shaheed-e-Millat Expressway, Shahra-e-Quaideen, North Nazimabad.



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- Developed a social media campaign revolving around 21 celebrities, including Zoe Viccaji, Behroz Sabzwari, Amin Guljee, Sheema Kirmani, Adnan Malik, Anoushey Ashraf and Nadia Hussain amongst many others, advocating the need for inclusion of individuals with Down syndrome in our society.
- Launched a children's book "Aiza Alina" to spread awareness about Down syndrome in young minds. Aiza and Alina is a story written by Hiba Masood and published by the Bookgroup.
- The carnival was attended by 1700 individuals who shared our dream of an inclusive society and stepped forward to celebrate inclusivity.



#### **KDSP Carnival 2016**

KDSP organized a carnival for individuals with Down syndrome, their families and friends of at the Beach Luxury Hotel on Sunday, March 20, 2016 to celebrate World Down Syndrome Day. The carnival lasted from 4 pm to 7:30 pm and individuals with Down syndrome, their families and friends of KDSP joined in for an evening full of fun, delicious food and exciting activities.

For the very first time, the very talented adult participants of the arts and crafts class at KDSP had a stall to themselves. The stall displayed nimbly crafted baskets, key chains, bags and decorative flowers. Each participant took turns managing the stall, proudly displaying their months of hardwork.

KDSP also launched a book titled "Aiza Alina" at the Carnival. The story revolves around two inseparable friends – Aiza and Alina of whom Aiza has Down syndrome. This story aims to create awareness in young minds that individuals with Down syndrome are more similar to us than they are different. The story was written by Hiba Masood and the book was published by the Bookgroup.

Other activities at the carnival included dance competition for children, games including spin-the-wheel, hit-the-sponge bowling, train rides for kids, photobooth, t-shirt painting and raffle drawing. The carnival was attended by 1700 who shared our dream of an inclusive society and stepped forward to celebrate inclusivity.



#### **KDSP Carnival 2016 Testimonials**

"This year I attended the KDSP carnival for the first time and my family and I enjoyed a lot. It was well organized and full of activities. My son, Muhammad Ziyam, is lucky to be part of KDSP. Well done!"

- Ambreen Asif

"It was great event and well organised. It was a pleasure to attend and we had and lots of fun there."
- Naghma Hussain

"The KDSP team did a great job. We enjoyed a lot during the carnival, including my baby girl with Down syndrome. The event gave families of individuals with Down syndrome to spread love amongst each other. It was a memorable day for me and my family. Keep it up!"

- Maryam Farhad Siddiqui

"Thanks for organizing such a wonderful carnival for those children with Down syndrome!"

- Sajeel Rizvi



### **KDSP Carnival 2016 Sponsers**

**Event Sponsors** 



TIBET

Deluxe





### **Gift Sponsors**







TIBET

Deluxe

#### **Video Sponsor**



#### Social Media Advertising Sponsor



### **Banner Sponsors**















## **KDSP Carnival 2016 Highlights**





## **KDSP Publications**

In 2015, KDSP successfully started publishing its quarterly newsletters titled "A Little Extra". The newsletters serve to raise awareness about Down syndrome and provides individuals with Down syndrome and their families to express their thoughts and share their experiences with the wider community. The newsletter also provides its readers information regarding recent activities held at KDSP. So far six issues have been published, each of which has reached out to an audience of over 600 people.









## **International Affiliations**

KDSP has developed international affiliations in order to share learning opportunities, experiences and professional expertise.

### **Down Syndrome Association Houston (DSAH)**

DSAH aims to provide programs and support to individuals with Down syndrome, their families, and the professionals who serve them, and to create awareness in the community through advocacy, education and medical outreach. DSAH facilitates KDSP's objectives through transfer of knowledge and information.

### Reach Pediatric Therapy Houston (RPTH)

RPTH is committed to providing innovative in-home and clinical treatment programs that specialize in pediatric rehabilitation services including physical, occupational and speech therapy. RPTH has recently started providing training to KDSP's speech therapists via Skype. In the future, RPTH also plans to provide online trainings to parents of children with Down syndrome on pediatric rehabilitation, in addition to providing professional networking opportunities for speech, occupational and physical therapists in Pakistan.

### **Down Syndrome Education International (DSEI)**

DSEI is a leading charity dedicated to raising levels of educational achievement among children with Down syndrome. The organization aims to transform the lives of young people with Down syndrome by improving understanding of their learning needs and by helping families and professionals to provide effective support, early intervention and education based on scientific research and evidence-based practices. Affiliation with DSEI has been indispensable in helping KDSP pioneer the Project for Inclusive Education.

# **Financials**

	2015-2016 (PKR)	
Income		
Donations	9,915,781	
Income from KDSP Carnival	8,357,015	
Therapy Income	191,000	
Program and events income	33,110	
Profit on bank account	412,783	
	18,909,689	
Expenditure		
Salaries and allowances	3,292,164	
Repair and maintenance	1,008,281	
Utilities	361,517	
Travelling and vehicle maintenance	313,953	
Printing, stationary and copying	518,877	
Educational and therapy goods	194,971	
Entertainment expenses	203,652	
KDSP carnival expenses	725,273	
Workshop consulting fee	1,237,462	
Depreciation	173,863	
Canteen expense	158,227	
Sports, toys and other supplies	192,396	
Subsidy on O.T clinics	116,750	
Membership fee	37,381	
Computer charges	48,305	
Legal and professional charges	10,600	
nsurance	12,467	
Advertising expenses	125,576	
Bank Charges	5,276	
Others	132,437	
	8,869,428	
Total comprehensive income for the period	10,040,261	



## **Contact us**

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### **Email & Online presence**

- info@kdsp.org.pk
- f www.facebook.com/kdsprogram
- www.kdsp.org.pk

#### **Donate**

Title of Account: Karachi Down Syndrome Program

Bank: Bank Al-Habib Ltd. Branch: Citi Tower Branch

Account Number: 1088-0081-003932-01-6

KDSP also has an option to donate online. Logon to www.kdsp.org.pk/donations for further details.

























