

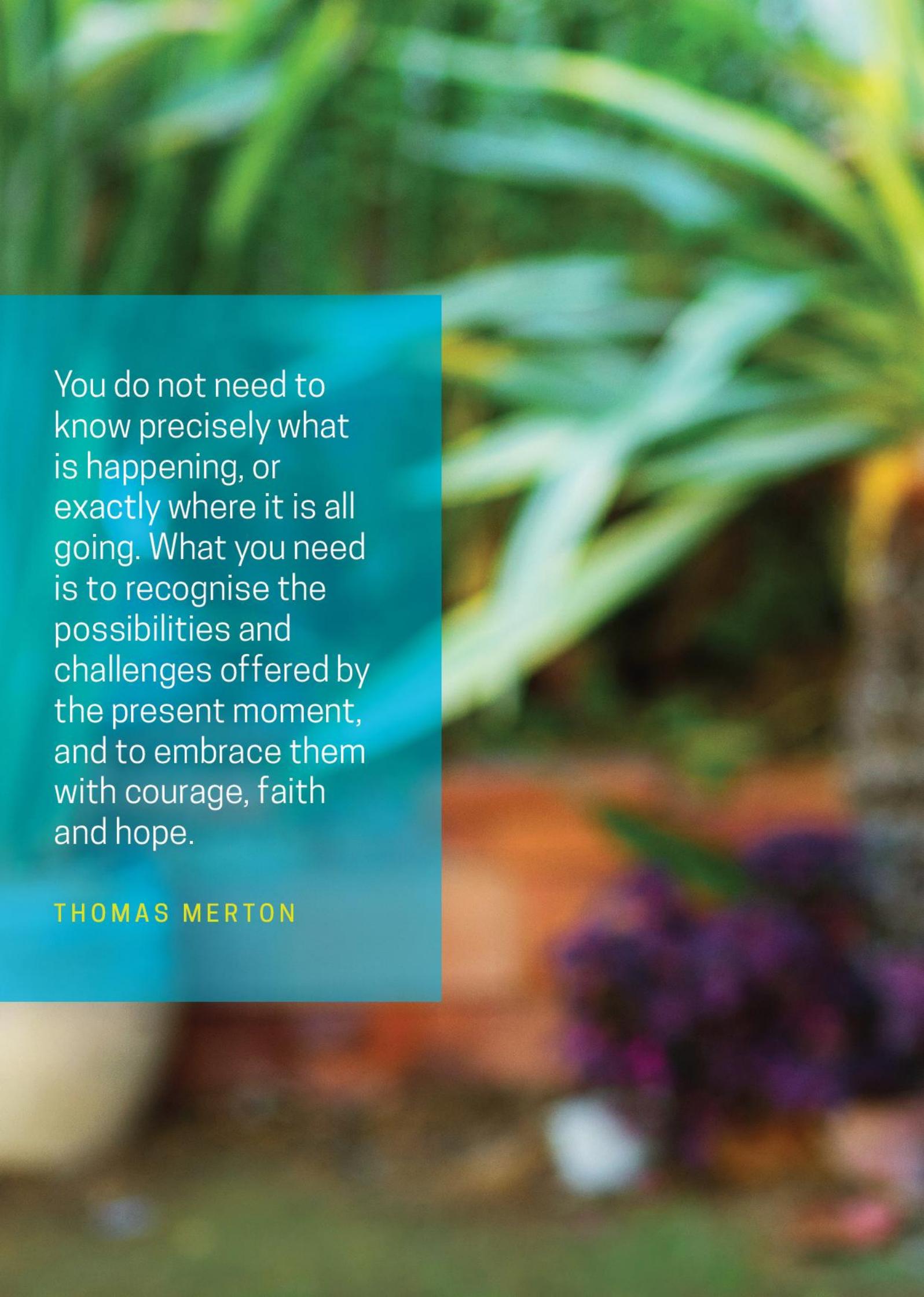
RECOGNISE THE POSSIBILITIES

ANNUAL REPORT | 2016-17



Karachi Down Syndrome Program

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



You do not need to know precisely what is happening, or exactly where it is all going. What you need is to recognise the possibilities and challenges offered by the present moment, and to embrace them with courage, faith and hope.

THOMAS MERTON



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About KDSP

The Karachi Down Syndrome Program (KDSP), a non-profit organization, was launched in March 2014 by a group of affected parents and passionate individuals who realized a need for a platform of those affected by Down syndrome was evident since the support and resources available to them locally were very limited.

KDSP was formed with the goal to advocate the value, acceptance and inclusion of people with Down syndrome living in Karachi and to provide them with the opportunity to lead fulfilling lives. Since its inception, KDSP has been involved in organizing seminars with international speakers and experts coming in, workshops, printing regular newsletters and establishing a helpline for parents, and partnering with educational institutions to promote inclusive education.

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.



Director's Message

Hello friends,

I feel honored to write the opening message for KDSP's Annual Report 2016-17. As for every young and growing organization, this has been an exciting year for us at KDSP as we continue to evolve rapidly. While we essentially remain a support and advocacy group for families of individuals with Down syndrome, we've strategically branched out into a few other areas. Updates on each area during this year are as follows:

- **Early Childhood Intervention (ECI)**

Effective and consistent ECI remains the key component in the development of any child with Down syndrome. By June 2017, KDSP was providing therapy to over 120 children mostly on a weekly basis as compared to 71 children the previous year. KDSP also entered into a strategic partnership with the Ziauddin College of Speech and Language Therapy through which well trained therapists working there are now providing quality therapy to children at KDSP.

■ Education

KDSP remains a strong advocate of promoting inclusive education for children with Down syndrome through our Project for Inclusive Education (PIE). We further our advocacy by partnering with mainstream schools in Karachi and training their faculty to handle the needs of children with Down syndrome. Our current partner school network has expanded to 14 schools across the city with 15 children with Down syndrome successfully enrolled into these schools. Learning from the Program for Inclusive Education, the team at KDSP is most excited as it plans to launch the Early Preschool Experience Program (EPEP) in August 2017, a one year program designed to prepare children with Down syndrome and their families for a smooth transition and settlement into mainstream schools the following year.

■ Healthcare

KDSP in collaboration with the Aga Khan University Hospital (AKUH) made a breakthrough when the two institutions collaborated in setting up the first specialized Down syndrome Clinic at the AKUH. This clinic will provide an inter-disciplinary approach towards health care for children with Down syndrome living in Pakistan and with better management of health, increase their chances to grow into contributing and independent members of society.

■ Enrichment Programs

KDSP continued its tradition to hold Family Support Group sessions and held nine sessions during this year. Speakers included specialists from the fields of Physical, Occupational and Speech Therapy, ENT, Genetics and Stress Management. This forum continues to grow as the pillar of support for families of children with Down syndrome allowing them to interact freely with one another and for their children to develop meaningful friendships with each other. Several other arts and sports based programs were also held at KDSP during the year.

The highlight for the year was indeed our World Down Syndrome Day Campaign 2017 which started off with the release of a music video of a song called "Aao Humaray Saath Chalo" written by Apa Zehra Nigah and sung by Ali Hamza, and ended with the annual KDSP Carnival.

The music video, produced by Amaan Ahmed and including celebrities such as Bushra Ansari, Javed Sheikh, and Sheema Kermani, highlighted how individuals with Down syndrome are more similar than different to us and how the society can benefit from being truly inclusive. I'd like to extend a special thanks to Hasan Rizvi for ensuring our message went out far and wide to our fellow Pakistanis and to Ali Hamza for putting his heart and soul into this song.

The KDSP Carnival was held for the third year in a row and was attended by approximately 3,000 people. The event was a true reflection of how powerful a truly inclusive society can be, where individuals with Down syndrome were our special guests for the day. I can't thank Aref Cheval and his team at Empact Activation Services enough for the love and dedication with which they make this event a success every year.

I also can't help but stress how much we value the generosity of our donors, sponsors and volunteers without whom it would be impossible for us to continue working towards our vision of creating an inclusive society, one where individuals with Down syndrome become valued members of our community. Please continue supporting us.

The biggest note of thanks goes out to our champions with Down syndrome for giving the entire team at KDSP the opportunity to work for them and in return make our lives joyful every day.



Ali Allawala
Chairman & CEO

KDSP Leadership

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

Ali Allawala
Chairman & CEO

Rashida Faheem
Director – Events
& Programs

Dr. Zehra Habib
Director – Early Intervention

Shakila Iqbal Allawala
Director – Fund Raising

Muhammad Ali Siddiqui
Director – Family
Support Group

Seema Zuberi
Director – Media &
Communication

Fauzia Hussain
Director – Education
& Training

Hamidah Walli
Head of Events, Programs
& Merchandise

Nasira Faiz
Director – Education
& Training

Farzeen Ali Allawala
Deputy Chief Executive

Dr. Jamal Ara
Director – Health Care

Our Goodwill Ambassadors



I have always believed that individuals with Down syndrome are wrongly labelled as 'dis-abled'. This label fails to take into account a plethora of unique abilities these individuals possess. We not only need to recognise these abilities, but also find ways to channelise it meaningfully to empower individuals with Down syndrome to become contributing members of our society.

I'm extremely proud to be an advocate of KDSP's mission of transforming the way Down syndrome is perceived in our society and providing individuals with Down syndrome with a platform to discover, enhance, and become known for their truly remarkable abilities.

Ali Hamza

Songwriter, Vocalist & Guitarist | Noori



Earlier this year I joined KDSP as their brand ambassador and I feel such pride in having joined this family. Working with kids with Down syndrome has brought immense joy in my life, along with that of my team members'. We are now more aware, more accepting and more grateful. These kids have showed us that they're equally capable of winning at life like anyone else and that they can prove to be contributing members of our society.

I believe we have the responsibility to give back to the society more than we take from it and I feel grateful to be in a position where I can spread the message of KDSP.

Hasan Rizvi

CEO, BBPR & Events

Music Director, Stage Actor & Choreographer



Areas of Service

Family Support Group

Enrichment
Programs

Early Childhood
Intervention

Healthcare

Education
and Training

Awareness

Family Support Group

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. Monthly Family Support Group (FSG) meetings at KDSP play an integral role in providing a platform for the families where their challenges of raising a person with Down syndrome can be addressed and resolved. These meetings are also a source of deep emotional support for families in a society that still has a long way to go in being truly inclusive.

In the year 2016-2017, KDSP successfully hosted 8 FSGs on various themes to empower parents of individuals with Down syndrome. Following are some of the past FSG topics and presenters from the preceding year:

	Date	Topic	Presenter
1.	July 23, 2016	Communication in Children with Down syndrome	Sadaf Shahid - Speech Language Pathologist, The Circle of Care
2.	August 20, 2016	Occupational Therapy for Children with Down syndrome	Nausheen Gul – Occupational Therapist, Milestones Charitable Trust
3.	September 17, 2016	An Introduction to Oral Placement Therapy for Speech Clarity & Feeding	Rohma Nadeem Akhtar - Speech & Language Therapist at DOW University of Sciences
4.	October 15, 2016	Stress Management for Parents of Children with Down syndrome	Dr. Shehla Khan – Associate Professor of Psychiatry, United Medical and Dental College
5.	November 26, 2016	ENT Care Needs for Individuals with Down syndrome	Dr. Mumtaz Jamshed – ENT Surgeon, Aga Khan University Hospital
6.	December 17, 2016	A Team Approach to Down syndrome	Dr. Salman Kirmani - Associate Professor - Department of Paediatrics and Child Health, Aga Khan University Hospital
7.	February 4, 2017	Augmentative Communication Strategies	Ms. Amina Siddiqui – Principal and Professor at Ziauddin College of Speech, Language and Hearing Sciences
8.	May 27, 2017	Siblings Issue	Dr. Ayesha Mian - Associate Professor & Chair, Department of Psychiatry, Aga Khan University Hospital

Altogether, these sessions empowered over 200 parents and caregivers with information useful for improving the quality of life for their family member with Down syndrome.

Early Childhood Intervention

Early Childhood Intervention therapies are offered at KDSP by professionals with a breadth of experience and knowledge. Therapy clinics run from Monday to Saturday from 9 am to 5:30 pm. All therapies are offered at KDSP at highly subsidized rates.

The physical therapy department is supervised by Dr. Zehra Habib, acclaimed as the only PhD in physical therapy in Pakistan. She also heads the physical therapy department at AKUH and serves as a lecturer there. Under Dr. Zehra's supervision, two full time physical therapists conduct clinics at KDSP.



KDSP also entered into a partnership with Ziauddin College of Speech and Language Therapy in June 2017 to offer high quality speech and language therapy by academically and clinically well qualified personnel to children with Down syndrome. Two full-time speech and language therapists are currently working at KDSP, and efforts are underway to hire more therapists to cater to the growing demand of the clinic.

The Occupational Therapy clinic is led by a therapist qualified from Dow University of Health Sciences.

No. of children benefiting from ECI Clinics

Therapy	2015-2016	2016-2017
Occupational Therapy	19	28
Physical Therapy	33	71
Speech Therapy	10	29

Education and Training

■ Project for Inclusive Education (PIE)

The aim of this project is to partner with mainstream educational institutions, provide them with best practices of inclusive education, train their faculty thrice a year to equip them with pedagogical tools customized for children with Down syndrome, and to 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.

Currently, KDSP has 14 active partner schools, which include:

- The AMI School
- CornerStones School
- Meezan Academy
- The Learning Tree
- The CAS School
- The Veritas Learning Circle
- The Anchorage School
- Little Heaven School
- The Elixir School
- The Educators
- The MCH School
- Berklee's
- Headway Grammar School
- Delsol



There are 15 children enrolled across these schools. KDSP's Education and Training department actively facilitated the teachers and parents of these children to develop their Individualized Education Plans (IEPs), which sets academic, social, cognitive, motor sensory, and self-help goals for each child in accordance to their developmental level. The department ensured that the IEP for each child was closely followed, and evaluated every six weeks.

■ Early Pre-School Experience Program

Taking into account the learnings from the pilot year of Program for Inclusive Education, KDSP aims to launch an Early Preschool Experience Program next year. The Early Preschool Experience Program (EPEP) will be 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 a relaxed, happy and secure environment for a child with Down syndrome, one in which he/she can develop socially, cognitively 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 basic concepts of 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.

Enrichment Programs

■ Candy Club Sessions

The Candy Club sessions were held between September 03, 2017 and November 5, 2017. In these sessions, the children participated in art based activities. Activities involved making structures using marshmallows and straws, and learning pottery making. The activities centered upon enhancing children's hand-eye coordination and fine motor skills.



■ Young Athletes

The program, launched in collaboration with Special Olympics Pakistan (SOP), took place weekly from December 2016 to. Special Olympics Young Athletes was a sport and play program for children between ages 2 to 7 years old. The program focused on developing basic sports skills in children like running, kicking and throwing. The curriculum for motor skills development was especially designed by Special Olympics Pakistan (SOP) with the purpose to help parents conduct play activities with their child at home using limited resources and ultimately prepare their children to compete in sporting competitions.



■ Yoga for Adults

This program was launched in association with Special Olympics Pakistan (SOP) in November 2016. Yoga meets both the physical and mental needs of individuals with Down syndrome. It enables young adults (aged 16 and above) with Down syndrome to strengthen the body, improve self-esteem, develop concentration and increase body awareness. Classes were conducted by Ms. Azmat, a certified yoga instructor and trainer from The Himalayan Institute, Pennsylvania, USA.



■ Arts and Crafts

The talented crafters from the previous year graduated to the advanced level of arts and crafts module under the guidance of Mr. Ussama, the founder and director of Candy Club - an organization for children which focuses on nature based learning. In the advanced level, participants learn different techniques of weaving and creating products that combine their sewing and embroidery skills with the art of weaving.

KDSP also welcomed a fresh cohort for the beginners' module. The classes are conducted by Mrs. Mahtab Pirzada, who is a home based crafts entrepreneur and a former creative consultant for the Sindh Rural Support Organization. Under Ms. Pirzada's guidance these young adults hone their fine motor skills and learn how to cut, sew and embroider. They learn how to make a variety of different products such as stuffed toys, mobile phone covers, bags, key chains, decorative flowers, etc.



■ KDSP Summer Camp

A fun filled summer camp was held from June 6, 2017 to June 22, 2017 for children between the ages 4-12 years. The summer camp incorporated three different modules: cooking, movement, and arts & crafts. The movement classes were conducted from Mr. Heera from BodyBeat Recreational Centre (BBRC). The children danced to rhythmic music and nursery rhymes, which helped reinforce their gross motor skills. The cooking classes were conducted by Ms. Rumana, a home-based food entrepreneur. Little chefs took great interest in making scrumptious food salad, sandwiches, Nutella pinwheels, and strawberry smoothie. It also aimed to strengthen the children's fine motor skills.

The arts and crafts classes were conducted by the Candy Club team. Here, the children enjoyed discovering their hidden talents as they engaged in hand-casting, block printing, and tie-and-dye t-shirt printing.



Healthcare

KDSP collaborated with the Aga Khan University Hospital (AKUH) in April 2017 to introduce a first of its kind one-stop health solution to facilitate children with Down syndrome and their parents.



Up until now, parents would struggle to find trained specialists who were able to look after the health challenges faced by children with Down syndrome. With the launch of the Down syndrome Clinic at AKUH, members registered as part of KDSP's Family Network database will be able to access subsidized and hassle free medical consultation being offered at the reputed hospital.

The launch event was attended by medical professionals and students, parents and families of people with Down syndrome as well as supporters. Since its launch in April, 69 children have benefitted from high quality healthcare services at affordable costs.



World Down Syndrome Day 2017

Launch of 'Aao Humaray Saath Chalo'

KDSP teamed up with Ali Hamza, its first Goodwill Ambassador, to release the music video titled 'Aao Humaray Saath Chalo' - a song written by Zehra Nigah and sung by Ali Hamza. The song highlighted how individuals with Down syndrome are more similar than different to us, and how the society can benefit by including them as one of us. Several renowned celebrities who supported KDSP's cause also appeared in the music video, including Bushra Ansari, Sarwat Gillani, Javed Sheikh, Ahsan Khan, Momal Sheikh, Anoushey Ashraf, and Sheema Kermani.



Participation in Aaj TV's Morning Show

Ali Allawala, the CEO and co-founder of KDSP, and Ali Hamza appeared on Aaj TV's morning show to talk about KDSP, Down syndrome, the importance of inclusion, and to reinforce how people with Down syndrome should be accepted as part of our society.



World Down Syndrome Day Carnival 2017

A Carnival to commemorate World Down Syndrome Day (WDSO) was held on Sunday, March 19, 2017 at the Beach Luxury Hotel, Karachi. Families of individuals with Down syndrome, along with Friends of KDSP, and the general public attended the Carnival. The carnival featured dancing competitions for kids, celebrity sightings, a photo booth by O'Shoot Photography, mini-train rides, delicious food, and lots of exciting prizes. Approximately 3000 people collectively demonstrated that KDSP's goal of an inclusive society is indeed possible, and that people of all abilities should be celebrated and appreciated.



KDSP Carnival 2017 Corporate Sponsors

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KDSP Publications

The newsletters published by KDSP is a step towards changing society's perception about Down syndrome and creating a more inclusive society for individuals with Down syndrome. It provides individuals with Down syndrome and their families to share their experiences, and inspire the wider community. The newsletter also provides its readers information regarding recent activities held at KDSP. In the past year, four newsletters were published, each of which reached to both local and international audience.





International Affiliations

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

- **Down Syndrome Association Houston (DSAHA)**

DSAHA 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. DSAHA facilitates KDSP's objectives through transfer of knowledge and information.

- **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.

Income and Expenditure Account

For The Year Ended June 30, 2017

	Note	2017	2016
		----- Rupees -----	
Income			
Donations		5,682,790	5,622,342
Income from KDSP Carnival	12	6,955,855	5,272,460
Therapy income		1,580,800	191,000
Program and Events income		86,200	22,910
Other income	13	571,691	324,938
		14,877,366	11,433,650
Expenditure			
Salaries and allowances		5,837,140	2,848,680
Repair and maintenance		1,555,136	506,156
Utilities		514,235	319,370
Travelling, conveyance and vehicle maintenance		103,555	294,333
Printing, stationery and copying		666,946	291,108
Educational and therapy goods		14,137	194,971
Entertainment expenses		179,228	163,878
KDSP carnival expenses		1,690,080	310,166
Workshop and consulting fee		53,013	1,237,462
Depreciation		193,440	133,306
Canteen expense		135,972	114,056
Sports, toys and other therapy related supplies		129,188	67,914
Subsidy on occupational therapy clinics		9,125	57,750
Subsidy on physical therapy clinics		55,225	-
Subsidy on speech therapy clinics		59,475	-
Membership fee		-	37,381
Computer charges		82,315	18,445
Legal and professional charges		56,000	10,600
Insurance		54,128	10,001
Advertising expense		67,046	7,256
Loss on revaluation of investments at fair value		224,766	-
Financial charges		68,222	3,006
Others		264,679	92,292
		12,013,051	6,718,131
Surplus for the year		<u>2,864,315</u>	<u>4,715,519</u>

The annexed notes 1 to 21 form an integral part of these financial statements.



Chief Executive Officer



Director

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Disclaimer

Legal Status and Nature of Operations

The Karachi Down Syndrome Program (KDSP) was incorporated in Pakistan as a company set up under section 42 of the Companies Ordinance, 1984. KDSP is primarily engaged in providing early intervention therapies to children with Down syndrome, enrichment programs for individuals with Down syndrome, support services for families of individuals with Down syndrome, and in raising awareness.

KDSP receives donations from organizations, institutions, and individuals to sustain the aforementioned activities. KDSP is an approved organization under sub-clause (c) of clause (36) of section 2 of the income tax ordinance 2001, so any individual, Association of Persons (AOP) or company donating is entitled to receive tax credit.

The registered office of KDSP is situated at Suite no. 102, First Floor, Jason Trade Centre, Shahra-e-Faisal, Karachi, Pakistan.

Contact Us

Should you have any questions or concerns about these policies and practices, please send us an e-mail at info@kdsp.org



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