

A LITTLE EXTRA

Karachi Down Syndrome Program's Quarterly Newsletter



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

Volume 4, Issue 2 | April 2018 to October 2018

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EDITORIAL

Hello Everyone!

After our carnival ended earlier in March, we had been busy building a new dream – literally! We are excited to announce that KDSP's office has expanded leaps and bounds under its recent expansion plan. More details about our recent expansion, along with other new initiatives taken, follows in the Activities at KDSP section.

In this issue, we are pleased to have featured endearing write ups by family members of those Down syndrome. Also, for the very first time, we have featured a short travel diary by Zahra Halai, an Assistant Teacher at our preschool program. With your love and endless support, we continue to strive to offer the best services for individuals with Down syndrome. May your love and support for continue to grow, just as our network of registered families is!

As always, we would love to hear more from you. Tell us what you liked, disliked or would wish to be different in the upcoming issues by writing to us at publications@kdsp.org.pk.

Happy Reading!



Karachi Down Syndrome Program

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

WHAT IS KARACHI DOWN SYNDROME PROGRAM?

KDSP is an organization formed by a group of parents and passionate individuals advocating the value, acceptance and inclusion of people with Down syndrome in Karachi.

SPEAK OUT

MAIN BHI TUM JAISA HOON

- Written by Ambreen Asif, Mother of Muahmmad Ziyam Asif



چلتا ہوں میں بھاگوں گا بھی
گروں گا تو میں سمبھالوں گا بھی
ہوں گا نہ میں کسی پے بوجھ
بدل دوں گا دنیا کی سوچ

جیسے ہوتے ہیں سب بچے
میں بھی بلکل ویسے ہوں

کاندھ سے کاندھا ملا کے چلوں گا دنیا کے ساتھ
میں بھی ہوں اتنول مجھ میں بھی ہے کچھ خاص
جگ بھر میں روشن روشن ہو جاؤں گا
ماں باپ کی شان برھاؤں گا

جیسے ہوتے ہیں سب بچے
میں بھی بلکل ویسے ہوں

جیسے ہوتے ہیں سب بچے
میں بھی بلکل ویسے ہوں
ماں کی گود میں ہنستا ہوں
چوٹ لگے گر روتا ہوں

جیسے ہوتے ہیں سب بچے
میں بھی بلکل ویسے ہوں

کیا غم ہے جو دیر کروں گا
سارے کام پر کر تو لوں گا
جب بنوں گا خود کی پہچان
دنیا کو کردوں گا حیراں

جیسے ہوتے ہیں سب بچے
میں بھی بلکل ویسے ہوں

ہاں میں بھی تم جیسا ہوں

XUNAIRAH'S JOURNEY

- Written by Huma Anjum, Mother of Xunairah Babar

9 years ago, on the birth of my second daughter Xunairah, a journey started. As soon as she was born, she was diagnosed with Down syndrome and a tiny hole in her heart, along with weak lungs. After her birth, a doctor painted a gloomy picture about how difficult my child's life would be. However, being an optimist, my husband and I were determined to make our daughter's life better than what we were told it would be. We promised to love her just as much as our other children and to never let her feel that she was any less of a person.

I gathered as much information as I could and reached out to anyone who could help. Soon I began home therapy sessions with Xunairah as suggested by professionals at a hospital in Lahore. Xunairah was about 2.5 years old when we moved back to Karachi. As soon as we came back, I wanted to enroll her into a decent school. With the help of a friend I was introduced to an NGO that provided me with a list of schools for Xunairah's admission. I contacted the schools on that list, but none of them agreed to give admission to my daughter as the admission process had already ended and they were not willing to make an exception.

Another friend of mine recommended me to enroll her into Milestone Charitable Trust. Here the admission directorate clearly told me that Xunairah was a perfectly fit to attend a mainstream school. However, due to unfortunate circumstance I insisted on enrolling my daughter in her school. And so began Xunairah's school life.

We were told by the Occupational Therapist and Speech Therapist at Xunairah's school that one-on-one therapy sessions will greatly benefit Xunairah. Following this, I began a search for a good therapist. I firmly believe that when Allah grants you a child with special needs, He also gives you the strength to provide every possible care and support for that child, and surrounds you with great people. Luckily we were able to find someone who became Xunairah's first speech and remedial therapist. There was a great change in Xunairah thanks to her. The following year I re-applied to a number of schools for Xunairah's admission but sadly, was left unattended.

I would also like to share my experience with a psychologist. Some schools required Xunairah's evaluation before giving her

SPEAK OUT

admission. For this, I visited a psychologist who gave Xunairah a very negative evaluation and told me that I should not hold any expectations of sending her to a mainstream school as she belonged to a special school. Even after informing her that I had done all my research regarding my daughters' condition which led to the fact that mainstream schools will benefit her more, her view remained the same. I was very disheartened by this but it did not stop me from doing what I believe was the best for my daughter. On advice of one of Xunairah's teachers, I enrolled her into CornerStone school. I met with the principal and really liked the overall environment. It has been 5 years since Xunairah started going to this school. She started off at PG level and is in Class 1 now. Due to her beaming smile and loving nature, Xunairah has successfully made many friends.

Xunairah is a member of Karachi Down Syndrome Program (KDSP) and Special Olympics Pakistan (SOP). She also participated in the previous 2 swimming camps organized by SOP.

I hope anyone who reads my story and my daughter's journey gains some positivity and confidence to deal with a similar situation.



SISTERLY LOVE

- Written by Cheryl Jason, Sister of Deborah Trisha

On being told their newborn baby has a special need, parents tend to react with a mixture of shock and disbelief, followed by denial. As the reality becomes irrefutable, feelings of guilt, fear of the reactions of others, and uncertainty regarding the future surface. On October 14, 2005 my family went through something similar as my sister, Deborah Trisha, was born with Down syndrome. My whole world turned around after the birth of this twinkly eyed angel.

I cannot forget the day my mother cried of helplessness. At that time I was preparing for my medical college aptitude test while my mother was working late hours. Seeing my mother in a hopeless condition, I wanted to step up and take a stand for the sake of my family, and more importantly, my sister. Rather than getting disappointed and dispirited I looked at the positive aspects of this situation and promised myself to make my sister's life just as typical as mine. I vowed to not let her down.

Loveable moments that I spend with Deborah make me realize how beautiful life is. Even with all our differences we look up to each other and find happiness and comfort in each other.



SPEAK OUT

It's true that our belief in ourselves and in our loved ones make us strong and gives us the power to conquer the world. I was strongly determined to give my sister a life full of happiness and good memories because she deserved it just as much as anyone else. Days went by and I noticed a very positive change in myself. Thanks to my beautiful sister I now have a bigger and better purpose in life. I feel like a completely new person and want to share all my positive energy and love with her. There have been many sleepless nights, ups and downs, and unsaid words, but all these things only made our bond stronger. Even in difficult times a smile from her can make my day a whole lot better.

We are usually told that people with Down syndrome require a lot of support from their family members. Although this is true to an extent, I believe that in our case the roles were reversed. The bond I share with Deborah is unmatched.

She understands me like no one ever can and recognizes my feelings before I even express them. She is my strength and source of my happiness. I cannot stress enough on how grateful I am to my Lord for blessing me his beautiful creation in the form of Deborah and for entrusting me with the responsibility of taking care of her.

The message I want to share is that Down syndrome is not a disability, rather it is an ability to see the world from a different perspective. All we require is a change in perspective to make this world more welcoming for those with Down syndrome.

ZAHRA'S TRAVEL DIARY

- Written by Zara Halai, Assistant Teacher - KDSP Early Preschool Experience Program (EPEP)

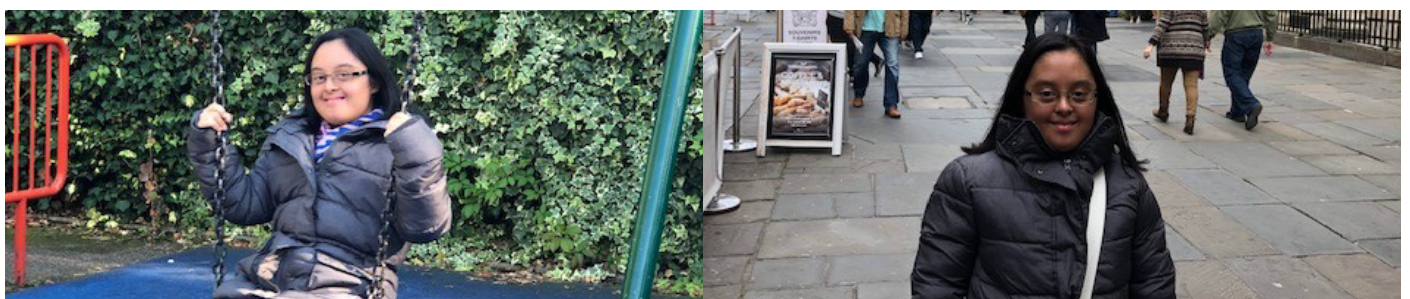
This year I went to London with my parents. London is one of my favorite cities, and I have been going there since I was two and a half months old. I have a lot of family and friends living in England.

On one of the weekends, we went to visit my uncle and aunt in Torquay, Devon. It is in the South of England and it took us 5 hours by car to get there. On the way we passed by Stonehenge, which was an amazing site. The giant stones were brought there hundreds of years ago by the Romans. We also saw the beautiful English country side with sheep, cows and horses in the fields.

Torquay is by the sea and it is very lively. I walked on the beach and the interesting thing is that instead of sand, the beach was covered with pebbles. I like sandy beaches.

One of my favourite desserts is the Devon Scones with clotted cream and strawberry jam. I always look forward to having it there, they are the best in the world! On our way back to London we stopped in the City of Bath. It is an old Roman City with cobbled streets and nice shops. I enjoyed shopping there. Bath is famous for its Ancient Romans Baths. We did not get a chance to see it because it was closing by the time we reached there.

Back in London, I went to my childhood park called Violet Hill. It brought back good memories. One of my favourite memories of the park is feeding the birds, going on the swings and playing on the jungle gym.



CREATING NEW OPPORTUNITIES

Sharoon Junaid is an eighteen-year-old boy, who did not have enough opportunities around him to allow him to excel. Sharoon was diagnosed with Down Syndrome, which led to his mother being incredibly protective of him. She cocooned him within the walls of his home, not allowing him to gain enough exposure to the rest of the world; though she meant well, this resulted in Sharoon not developing enough confidence to communicate with people aside from his family.

Unfortunately two years ago, Sharoon's mother passed away. This left his father incredibly concerned with the welfare of his child, as there was no longer someone at home to constantly look after him. He wanted the best for him, and realised there may be organisations that could help his child develop his skills better. Therefore, on the 21st of January 2018, Sharoon's father took his son to the National Disability Forum (NDF). The day team Special Olympics Pakistan (SOP) visited NDF for the first time on 20th June 2018, Sharoon took great interest in the sports activities and was happy playing around during the Young Athletes (YA) activities. The NDF further recommended Sharoon's father to look into SOP. He was impressed by the

scope of work that was being conducted and brought Sharoon over to the camps of SOP, and was immediately delighted to see how well Sharoon fit in with the other kids. Sharoon took an interest in not one but numerous sports. While he was the best at Football, he also thoroughly enjoyed Athletics, Cycling and Basketball.

Special Olympics Pakistan aided Sharoon in interacting with people whom he shared many similarities with. Introducing Sharoon to an organisation designed to cater to individuals with special needs, not only helped him understand himself and his abilities better, but also enabled him to find a passion within something he had never thought of. Sharoon has been registered with SOP as an athlete and will be invited for future camps and events.

- Contributed by Tehmina Azim, Special Olympics Pakistan

EXTRA SPECIAL QUOTE

“LIVING WITHOUT MEETING A CHILD WITH DOWN SYNDROME IS LIKE EATING A CAKE WITHOUT SUGAR. TOLERABLE, BUT NOT SPECIAL.”

- Zara Ahmed, Sister of Sara Ahmed



ACTIVITIES AT KDSP



ARTS AND CRAFTS

Our exceptionally talented participants of arts and craft class made innovative products throughout the previous months, including stuffed rabbits, doll, cat, heart keychains, and hand embroidered cushions. Their work is greatly appreciated by the visitors who come to KDSP and at various exhibitions were their products are sold on their behalf.

MUSIC AND MOVEMENT WITH FAIZAN

KDSP started a Music and Movement session in July 2018 for children with Down syndrome between 8 to 18 years of age. The weekly sessions engages 10 participants, and aims to improve the gross motor function, enhance self-confidence, creativity, and social skills through musical and play-based activities.



GYMBOREE PLAY AND MUSIC

A team from Gymboree Play & Music heads over to KDSP to hold fun play activities for children between 3-7 years of age. The team uses various activities and props to focus on building a daily living concept. These activities help develop the mind, body and imagination in one-of-a-kind environment for the participants.

KDSP SUMMER CAMP 2018

The Summer Camp 2018 hosted from Tuesday, May 22, 2018 to Saturday, June 9, 2018 kicked off with arts and craft activity where our highly talented participants were seen creating customised tote bags and bird houses. Every new day was followed by a new activity such as cooking class, Mango fest, music class, clay modeling and much more. A trip was taken to Topsy Turvy Playland to wrap up the summer camp. Thank you Ghazal Pirzada Creative Studios, Candy Club, Topsy Turvy, and Sugaries for collaborating with KDSP!



MINDFUL ART WEEK FOR SIBLINGS

KDSP conducted a Mindful Art Week for Siblings aged 9-14 years of those with Down syndrome from June 25 – June 29, 2018. These sessions provided siblings of kids with Down syndrome a safe and positive space to explore their feelings and express themselves through creative and mindfulness-based art. They were also able to meet peers like themselves and develop friendships borne out of similar experiences. The sessions were conducted by Ms. Farzeen Ali, Co-founder and Deputy CEO at KDSP, and trained in art therapy and mindfulness.



PLAY KYUN NIKALA FUNDRAISER

As part of its fundraising initiative, KDSP bought out a show of the renowned play Kyun Nikala, written by the maestro Anwar Maqsood and directed by Dawar Mehmood on Monday, September 10, 2018 at the Arts Council, Karachi. KDSP's exclusive night of the show was generously sponsored by Hilton Pharma Pvt. Ltd. Through ticket sales, sponsorship, and donations by the audience, KDSP was able to generate considerable funds to sustain its quality services for those with Down syndrome.

ACTIVITIES AT KDSP

STORYTIME WITH NAZIA

Storytime sessions are held monthly for kids between 4-8 years of age. The storyteller, Nazia, engages the attention of the participants with melodious songs and thrilling stories. These sessions are very much loved by the kids as in every class they get to read a new story and derive a new lesson from them.

EARLY PRESCHOOL EXPERIENCE PROGRAM ORIENTATION

The orientation for KDSP's Early Preschool Experience Program (EPEP)'s academic year 2018-2019 was held on Saturday, September 15, 2018. The children were introduced to their new playground, class room, teachers and classmates. The parents too were introduced to the curriculum and strategies to ensure optimal learning for their child. of the most pressing behavioural concerns parents had about their children.



KDSP NEW FLOOR INAUGURATION

On Monday, September 17 2018, KDSP announced the inauguration of KDSP's new premises on the fifth floor of the Jason Trade Centre. This new area is dedicated to the stars of KDSP to ensure better learning as it comprises of several new therapy clinics, counselling room, vocational training room and an activity room. With this achievement we hope to be able to cater to the needs of a greater number of individuals with Down syndrome and their families.

FAMILY SUPPORT GROUP SESSIONS

Once every month a Family Support Group session is held at KDSP where the parents and family members of individuals with Down syndrome are invited to a highly informative session regarding a specific condition related to Down syndrome. Details of the sessions held in the past month are:

Session No.	Date	Topic	Speaker	No. of Attendees
34	May 12, 2018	Importance of Speech Therapy for Children with Down Syndrome and Related Strategies	Dr. Amina Siddiqui	33
35	Sept 22, 2018	ENT Care Needs of Children with Down Syndrome	Dr. Moghira Siddiqui	35
36	Oct 27, 2018	The Importance of Cardiac Care for Children with Down Syndrome	Dr. Babar Hasan	16



INCLUSIVE EDUCATION TRAINING

As part of its Project for Inclusive Education (PIE), KDSP hosting a 2 day training on Inclusive Education for teachers of children enrolled in KDSP's partner schools, and parents of those children. The first day of the training give the teachers an introduction to inclusive education and its best practices. The second day of the training centered upon learning how to develop Individualized Education Plans (IEPs), where the parents and teachers sat together to develop IEPs for children.

VISIT TO SPARK PLAYCENTER

KDSP & SPARK collaborated to celebrate Down Syndrome Awareness Month. Children along with their siblings paid a visit to the SPARK play center on Tuesday, October 30, 2018. We would like to thank the team at SPARK for being a wonderful host and for choosing us to celebrate this event with.



EVERY LITTLE CONTRIBUTION COUNTS!

Help us sustain the services we offer for individuals with Down syndrome and their families. Following are the ways in which you can make a donation:

BANK TRANSFER

KDSP Bank Account Details:
Account Title: Karachi Down Syndrome Program
Bank Name: Bank Al Habib Limited
Bank Branch: Citi Tower Branch
Account Number: 1088-0081-003932-01-6
IBAN: PK53 BAH1 1088008100393201
Swift Code: BAHLPKK

ONLINE TRANSFER

Please log on to
<https://www.kdsp.org.pk/get-involved/donation/bank-donation>
to pay via our secure payment gateway

CROSSED CHEQUE

A crossed cheque in favour of "Karachi Down Syndrome Program" can be sent to the following address:
Suite no. 102, first floor, Jason Trade Centre Shakra-e-Faisal, Karachi



Karachi Down Syndrome Program

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

Karachi Down Syndrome Program

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