

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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EDITORIAL

Welcome to the fourth edition of the KDSP Newsletter! The past few months had been extremely busy for the KDSP team as we were engrossed in carnival preparations; meticulously streamlining everything so that all the attendees had a time of their lives, whilst proving that an inclusive society is indeed attainable.

We are also immensely proud to announce the launch of our book "Aiza and Alina" – a story of two friends one of whom has Down syndrome. The launch of this book serves as a stepping stone towards our determination to create acceptance for individuals with Down syndrome in our society.

The present newsletter edition will offer a detailed coverage of the carnival and the awareness campaign that led up to it. A brief introduction of the book "Aiza and Alina" has also been included. Besides, this we're excited to have published heartwarming poems by a mother and sibling of a child with Down syndrome, two stories of inspiring experiences and much more!

Please write in to us anytime at publications@kdsp.org.pk with any comments or queries. We look forward to hearing from you!

Best wishes,
Team at 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.

CELEBRATING INCLUSIVITY

KDSP CARNIVAL 2015



KDSP organized a carnival at the beach Luxury Hotel to celebrate World Down Syndrome Day on Sunday, March 20, 2016.

The carnival lasted from 4 pm to 7:30 pm and offered something for everyone! There were exciting games and activities for kids, raffle prizes for the adults and scrumptious food for all!

The venue was abuzz with excited squeals of kids as they won one game after another and rushed off to the KDSP counters to collect their gift bags. One of the most colourful stalls was of t shirt painting.

The children waited patiently in a queue awaiting their turn display their creative abilities by painting t-shirts. They were given coloured spray paints which they used to create vibrant patterns on a plain white t-shirt which they were then given to take home with them.

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 with a group of volunteers proudly displaying their months of hardwork.

Excitement during the carnival heightened when Zoe Viccaji arrived. She sung melodious songs to which the audience had a delightful time singing along to.



During the much awaited dance competition, children danced to upbeat music. The amount of fun the younger ones were having was evident from their glowing faces, bright smiles and animated dance moves. The competition ended and every kid was such a talented dancer, that they all were declared as winners and given prizes!

Once tired with all the fun games and artsy activities, everyone made their way to the food area. The food area offered popcorn, pizza, fries, ice cream, brownies, chowmein, sandwiches, chaat and lemonade which was enough to satiate everyone's hunger pangs!

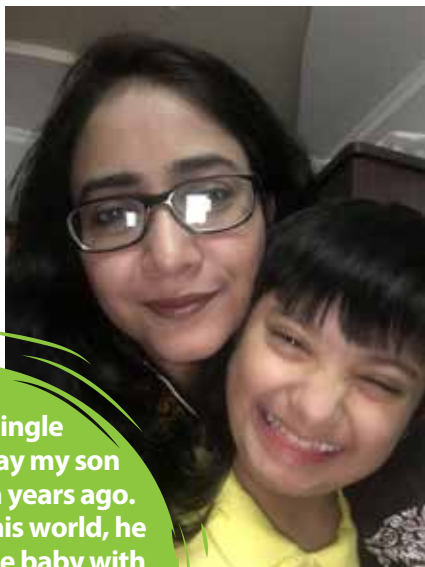
We would like to thank all our supporters who shared our dream of an inclusive society and stepped forward to celebrate inclusivity. A special thank you to all our volunteers our event managers (The Brand Crew), our social media advertising sponsor (Ailaan Advertising), our event sponsors (Coca Cola, Habib Metro, Tibet) Our gift sponsors (EBM, Candyland, Unilever and Tibet) and our banner sponsors (GSK, Orix Leasing, Mujahid Foam, Medinostic, Tricom Power, ResourceLinked, JCR Credit Rating and

TML Activation). We can't wait until the next carnival! Can you?



SPEAKOUT

My Son, Mahad!



I have been a single mother since the day my son Mahad was born ten years ago. When he arrived in this world, he was an extremely cute baby with very unique features. We wondered how he got these facial features as all of my family members have sharp features.

The doctor informed me that Mahad has Down syndrome. Upon hearing this, an alarm bell started ringing in my mind: What is the difference? Where is the difference? O God why in my son? How can I make him normal? I was nervous; I had no idea what he was talking about, and what was meant by Down syndrome. I was really very disturbed and different kinds of ideas started popping in my mind. The darkness and fear I experienced were unlike any other fear. The doctors could not have been more discouraging. I rushed to my family physician who told me that Mahad is typical in all respects except that he has one extra chromosome. Nothing could be done to remove that one extra chromosome. He politely told me that due to this situation, his growth will be a bit delayed as compared to typically developing children.

It was that time that I became aware that Down syndrome is the most common chromosome disorder. At the spur of the moment, I promised myself that I will dedicate my life for my sweet angel. I will do whatever I could to make him fully independent enable him to lead a fulfilling life.

As I am a working woman, Mahad was admitted in day care centre. His days at home at the day care center were excellent. He was loved by all as he was the most innocent child. A cheerful smile always played on his face and he never cried.

When the time came to admit Mahad into a school, it was the worst experience. Mainstream schools refused to admit him as he was different. Special schools declined admission as Mahad's diagnosis

was very mild. Finally, he was admitted in a reputed mainstream school which offered inclusive education. The education he received there was excellent and allowed him to learn quickly. However, when he was admitted into mainstream education system, the process of learning was reversed. He was neither accepted by the teacher nor by his peers. They called him slow, goofy and lazy. He learnt nothing, forgot all he had previously learnt and developed a sense of inferiority. I met with the class teacher, who plainly told that she was not supposed to focus on him as his pace of learning is slow. Eventually, I approached the school management, who did not accept the fact that he was being bullied at school. They rudely told me "Open your own school if you want him to receive full attention."

These sarcastic remarks of opening a school of my own did not dampen my soul. I decided to do just that. I decided to create a haven for my son as well as for all those kids who are not being given what they genuinely deserve. I want to gain satisfaction of offering the best learning opportunities to my son as well as all kids with the special condition. I also wanted to make my son as independent as possible.

As fortune favours the brave, I started the project. God gave me chances. My dream of creating an independent facility for children with Down syndrome converted into a reality in the name of Seventh Heaven School. I invite all of you to visit my school. Its address is 92-H, PECHS Block-6, near Madni Masjid, Ambala Bakers Road, Karachi.

Now my baby is just like any other child! He loves to play with his stuffed toys and takes great care of them. He always protests when it is time to pick up the mess. He loves to play tag and watch kid's dramas and all kinds of humorous plays. He fights sleep at bed time, and wakes up with a smile and a kiss for his Mommy. He enjoys his bath time too. He has now made many friends and has become quite social. He has lots of interests too: he loves to be outdoors on swings and joyrides and regularly attends Taekwondo classes.

Looking after Mahad has made me stronger. Honestly, although a fear of the unknown was always there right from the beginning, but I never thought it would be a major problem that I had to overcome, and it really hasn't been. My son will probably never get into top universities of the city or become a rocket scientist. But that's not going to disappoint me because I didn't do that either. I'm going to celebrate what he can achieve and not worry about what he can't.

Saima Jamali, Mother of Mahad

ASIM ZAR – THE SHINING STAR

The 27 year old Asim Zar made headlines last year in October for bagging a gold medal in the aquatics competition in the Special Olympics World Summer Games 2015 held in Los Angeles. Who knew that the little boy who was scared to dip his feet into the pool would make his country and family immensely proud! Asim and his mother Tehmina Azim joined the KDSP team to talk about Asim's inspiring journey and the barriers he bravely overcame throughout the years leading up to his recent achievement.

As a young child, Asim was unable to walk at all due to weak muscle tone. He was also unable to speak and used sign language for communication. "The child specialist always told me not to worry, but I could never stop worrying."

Asim used to be tremendously hyper as a child. When he went to parks, would run around excitedly and hit other children who came into his proximity. Since he couldn't speak at the time, it was his way of communicating with other children. "Everyone used to taunt us for not taking care of him, and just leaving him without supervision. But that wasn't true. Gradually, people started isolating us, and more so when they found out that Asim had Down syndrome. They did not accept him. They laughed at him, made fun of him and blamed us for being irresponsible towards him."

When Asim was three and a half years old, he was admitted into a school. The teachers noticed that he was eager when his fellow classmates sang the national anthem during the morning assembly every day. He too wanted to sing along with them, but he was never able to utter words despite trying. Upon his teacher's recommendation, Asim was taken to a speech therapist. "After two and a half months of speech therapy, the therapist called my husband and I to his office one day. He was the one who suggested that we should get his karyotyping done. He explicitly told us that Asim would always fall short of our expectations. Little did we know that he would exceed all our expectations in just a few years." Tehmina added with a laugh.

The positive test results of the karyotype brought a shock to Asim's family. At that time there was very little awareness of Down syndrome. This was a big challenge for us. But we didn't lose hope. I then started reading books about Down syndrome to gather information about it. Asim was diagnosed with translocation Down syndrome in which one chromosome breaks off and attaches to another chromosome. In this case, there are three 21 chromosomes but one of the 21 chromosomes is attached to another chromosome.

Later, when Asim's family transferred to Lahore, he had to be placed into a different school. In those days the concept of inclusive education did not exist and the only option his parents had was to put him into a special school. After extensive searching, Asim's father eventually found a special school which he believed would offer a conducive environment for Asim. "We owe the headmistress of that school for raising our hopes and motivating us to push Asim towards athletics." Subsequently, Asim's journey as an athlete truly began when he was only seven years old. He participated in the Punjab Olympics in the under the category of athletics and that was the first time he won a gold medal.



When we shifted to Karachi, the teacher in Asim's new school started grooming him really well. In 2007 he was selected for China World Games in the category of athletics and long jump. "Once when I went to drop Asim to the railway station for the training camps prior to the competition in China, and I saw the train compartment in which Asim had to travel to Lahore for his training camp, I literally felt like crying. It was in a deplorable condition! I was horrified to think that my son had to cover a huge distance till Lahore in such a train compartment. I fought with the administration and asked them to change the compartment or choose another train altogether. But it was too late for such changes to be made. Asim's teacher there consoled me saying that there are other kids and all other coaches too going with him; he isn't alone. I was worried that something might happen to Asim. But she consoled me that nothing will happen to Asim, just trust us. I had no choice at this last moment but to let Asim go with a heavy heart."

Asim returned with two gleaming silver medals along with renewed self-confidence. Much to everyone's surprise, he had transformed into an exceptionally confident child within a short span of a week. Living independently had instilled an enduring sense of self-confidence in him. It was this confidence in his abilities that Asim gained at the expense of his comfort.

Asim then found an interest for swimming. Initially when he was enrolled for swimming classes, he was extremely scared to even dip his feet into the water. "We were extremely worried as to how can we help him overcome this fear of water. He would go for swimming along with his siblings, all his siblings would have fun swimming, but Asim would just sit in the corner and refuse to go near the water." The coach gradually helped Asim overcome his fear for water and eventually he was trained to swim within 6-7 months.

In the recent Special Olympics World Games 2015, Asim won a gold medal in the 100 meters freestyle aquatics competition clocking in a time of 00:02:29.56. He also got a chance to interact with international participants of other countries and learn from them.

"I find comfort in the fact that Asim has now become independent. He is now employed in the packaging department in a factory. He truly enjoys his work and has made many friends there."

In future Asim plans to diversify his experience by participating in cycling competitions. Had it not been for Asim's enduring bravery and effort, along with and concerted support from his family, Asim would not have been able to spread his wings to take flight towards success. We hope that Asim continues to make us all proud in many more years to come!

ONE PLUS ONE EQUALS TWO



*One plus one equals two, you see,
But somehow it's different with you and me.
When we're together, we share one mind.
A happier pair you'll never find.
I'm only complete when you are near.
To lose you someday is my biggest fear.
You know my dreams and my every thought.
No stronger bond could ever be sought.
We have a lot in common. it's true.
But who'd have thought, who'd ever knew?
Twins we're not,
But I'm not complete unless you're with me.
We're more than friends
With you as my sister, I feel 10 feet tall.
As sisters and friends, we're quite a pair.
One soul, one mind is what we share.
You make my world a better place.
I live each day to see your face.
It takes two halves to make a whole.
My heart and yours, we make one soul*

Written by sister of Deborah Trisha

WO DIN BHI YAAD HAI

ڈاکٹر کی آواز نے توڑا سحر میرا،
 پھلا دیا چاروں طرف اندھیرا ہی اندھیرا،
 میری چھایا مختلف ہے سب سے،
 سہی نہ کر پائے گی کوئی کام امید نہ کرنا اُس سے،
 جب وہ چلتی نہ تھی، بولتی نہ تھی، بھاگتی نہ تھی،
 آنسوں تھکتے نہ تھے میرے اور کوئی امید نہ تھی،
 پھر اپنوں نے میرا حوصلہ بڑھایا،
 میں نے اور دیوراہ نے پہلا قدم اٹھایا،
 پھر ہم چلتے ہی رہے لوگوں کے ہجوم میں،
 طویل راستہ، گھٹن مراحل اور فکر میں رہی ثابت قدم،
 ۴ اپریل کو لیا میری بچی نے انکلوزف اسکول میں قدم،
 آج بھی آنسوں تھکتے نہیں رکتے نہیں میرے،
 فرشتے کہ لیے جس نے دی یہ دولت بیش بہا مجھے،



Written by Slomica Naveed, Mother of Debroah Trisha

VOLUNTEER SPOTLIGHT

I came to know about KDSP through a seminar held on "International Day of People with Disabilities" in December 2014, where Mr. Ali Allawala came as a guest speaker. He shared his experience with us and introduced us to KDSP which had been newly established at that time. He also offered us the opportunity of volunteering at KDSP. As I was greatly inspired by this new organization, I registered my name as a volunteer in the first opportunity.

Since then I have volunteered for various events at KDSP. I have participated in monthly Family Support Group Sessions where we engaged children in different activities such as drawing, painting and games while their parents attended the lecture session. I also volunteered for a trip to KidzDunya at Dolmen Mall Clifton where I was responsible for taking care of the children and engaging them in different activities such as baking pizza and performing role playing games.

Quite recently, I volunteered the KDSP Carnival held at the Beach Luxury hotel where I had a great time helping them at the stage. I also took the children for the train ride and helped manage the KDSP handicrafts stall which sold handicrafts made by adult participants of the weekly arts and crafts classes held at KDSP. I, along with my friends, was also involved in the pre-carnival preparations. Everyone worked in groups to prepare goody bags for the carnival. We had an incredibly fun time while doing so. Once, we even held a small competition to see who made goody bags the fastest and to our delight, the person who won received chocolates and snacks as a prize!

Being a part of KDSP was more than a relationship of work and the reason of my motivation is KDSP itself. Volunteering at KDSP has proven to be a great boost for my career as well. I will never miss out on another chance of working with them again!

Madiha Arshad is currently doing her Masters in Special Education from University of Karachi.



ACTIVITIES AT KDSP!

FAMILY SUPPORT GROUP SESSION 16

The 16th Family Support Group Session was held on the topic “ENT care needs for individuals with Down syndrome.” Dr. Moghira Siddiqui, an ENT specialist from Aga Khan University Hospital spoke on the common ENT issues faced by individuals with Down syndrome, how to identify them and also discussed their treatment. The session was attended by 35 parents and caregivers.



ARTS AND CRAFTS FOR ADULTS – January to March

Throughout January was extremely busy. With the carnival just round the corner, the participants were bent on transforming their creative imagination into material products which could be sold at the carnival.

All the proceeds from the sale of each participant's products were returned to them in order to encourage them to become financially independent.



World Down Syndrome Day Campaign

21 Celebrities

A social media campaign was launched beginning March 01 and lasting until March 21. This campaign featured 21 celebrities including Zoe Viccaji, Behroz Sabzwari, Amin Guljee, Sheema Kirmani, Adnan Malik, Anoushey Ashraf and Nadia Hussain amongst many others. The campaign focused on raising awareness about Down syndrome and each celebrity individually stressed upon the importance creating an inclusive society for individuals with Down syndrome.

21 billboards

21 billboards were put up in all major areas of Karachi to create awareness about Down syndrome to symbolize 21 chromosomes.



AAJ TV morning show

Mr. and Ms. Ali Siddiqui and Mr. and Mrs. Syed Kaleem appeared on the AAJ TV morning show "Aaj Subh with Nusrat Haris" on World Down Syndrome Day. These proud parents of children with Down syndrome debunked some of the most common misconceptions about Down syndrome and stressed on the fact that children with Down syndrome are much like typically developed children. They need to be loved and cared for rather than alienated by the society.

AIZA AND ALINA

Aiza and Alina is a story written by Hiba Masood and published by the Bookgroup. The book was launched at the KDSP Carnival 2016. This heartwarming story aims to create awareness in young minds that individuals with Down syndrome are more similar to us than they are different. The story revolves around the story of two inseparable friends – Aiza and Alina – who share the same interest and love for kittens. One day Alina comes to know that Aiza has Down syndrome. Does that modify the strong bond of friendship between the two girls? How does Alina react? Grab your own copies to find out more!

To purchase, call us on 021-34315377 or 0334-3355377

Price:
RS.200



HEALTH AND DEVELOPMENT

Inculcating reading skills in children with Down syndrome

The value of learning to read cannot be underestimated. Reading is a key part of human communication and key to participation and inclusion in society. Engagement with texts fosters development of a wider understanding of the world in which we live. A parent or a caregiver can boost a child's language, memory and intellectual development by simply making books an integral part of their life.

Children with Down syndrome learn how to read in the same way as typically developing children. However, children with Down syndrome tend to have more receptive than expressive language skills. This means that they can understand far more than they can verbally express. For most children, oral language skills develop prior to reading. However, for children with Down syndrome, reading can provide a concrete pathway for oral language development.

Children with Down syndrome may encounter difficulty in learning the relationships between letter, sounds and the formation of sounds into words. Children with Down syndrome begin recognizing words as a whole first. Such words are referred to as sight words. As they develop, they gradually begin to learn to decode words with respect to their sound components.

As children with Down syndrome are visual learners. As children with Down syndrome are visual learners, they are mostly attracted to visual forms of presentations. One of the most effective techniques to foster reading skills in children with Down syndrome is to use word-to-picture associations. Flashcards are proven to be able to attract the attention of children with Down syndrome and is easier to remember the outcome of the learning. The visual image helps provide the children with a frame of reference through which they can recall the name of a particular object when they encounter in real life.

It is essential to encourage word imitation. Repeat a word after it has been said or signed to reinforce it in the child's vocabulary. Repeating the word also serves as a model for correct pronunciation. Here are some additional useful strategies to help your child to read:

- Set apart 15 -20 minutes of reading time for your child every day.
- Let your child choose what to read.
- Serve as a role model for your child and indulge in leisure reading yourself.
- Play word-action games where you say a word out a loud and ask your child to enact it.
- Let your child set their own pace for learning. Do not rush them through the process.

Reading is a key life skill. Learning how to read may be a long process, but it is not a difficult process. Be patient and make the learning process enjoyable for both you and your child!

Debunking Myths: Reading Development in Children with Down Syndrome. Australian Journal of Teacher Education (2013)
www.downsyndrome.org



Karachi Down Syndrome Program

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