

A LITTLE EXTRA

Karachi Down Syndrome Program's Quarterly Newsletter

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



VOLUME 2, ISSUE 1: OCTOBER 2015 TO DECEMBER 2015

IN THIS ISSUE:

Editorial	Page 1
Aspiring to Inspire	Page 2
Speak Out!	Page 4
Color Splash	Page 5
Born this way!	Page 5
Volunteer Spotlight	Page 6
Activities at KDSP	Page 6
Health and Development	Page 8

EDITORIAL

Greetings and a very warm welcome to the 3rd issue of A Little Extra! In this issue we have included brief inspiring stories of nine successful individuals with Down syndrome to prove that individuals with Down syndrome too can be active member of the society and serve as role models for all. The issue also brings to you a detailed summary of all the events held at KDSP through the months October to December.

We would like to thank all the parents and caregivers who reach out to us to share inspiring experiences and lovely photos with us. Please keep them coming! We are thrilled to share some of these write ups in with friends of KDSP and the larger community.

We hope that you will find this issue both interesting and informative. Please write in to us at publications@kdsp.org.pk with any comment, queries or feedback. We always 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.

ASPIRING TO INSPIRE

Successful People with Down Syndrome

A false perception commonly pervasive in our society is that individuals with Down syndrome are unable to lead a life of normalcy. It is said that believe you can and you are half way there. The following inspiring individuals with Down syndrome prove that joy and success are attainable to anyone, regardless of a genetic condition.

Angela Bachiller

Angela is the world's first person to hold a public office and to pursue a political career. In 2013 Angela became the first person with Down syndrome ever to be elected councilwoman for her town in the Spanish city of Valladolid. She worked for three years in Social Welfare and Family as an administrative assistant, and loves reading and traveling. She hopes to be representative of individuals with Down syndrome in a public arena and make a difference in the lives of those with disabilities.



The first person with Down syndrome to graduate with honors from a technical college, Megan attended Bluegrass Community Technical College. She wants to work in education at the elementary level to serve as a role model for them. She proves that with the right backing and resources, people anywhere can reach their goals, regardless of their genetic conditions.

Megan McCormick

Tim Harris

Tim is the owner of his own restaurant known as Tim's Place. He graduated from college with certificates in Food Services, Office Skills, and Restaurant Hosting. He dreamed of owning a restaurant, so he found jobs in the industry to learn as much as he could. The restaurant opened its doors in 2010 and served American and New Mexican cuisines, along with free hugs to each visitor by Tim himself! According to a former employer, Red Robin says that the store's revenue went up during Tim's shifts. However, Tim recently announced that he will be closing down his restaurant to marry Tiffani Johnson; a girl with Down syndrome who he fell in love with. Additionally, Tim also created Tim's Big Heart Foundation to help other people with disabilities start their own businesses.



Pablo earned a bachelor's degree in educational psychology and a diploma in teaching. He went on to become a writer, speaker, and actor. Born in Spain, he is a successful actor in his home country, and has also received the Silver Shell award for his acting skills as well as the San Sebastian International Film Festival's "Concha de Plata" as best actor of 2009 for his lead role in the film Yo Tambien in which he played the role of a university student with Down syndrome.

Pablo Pineda

Christian Royal

School never came easy to Christian, but that is just fine because he holds a skill many of us admire. Since his teen years, Christian showed a knack of working with clay. He began making pottery as part of the homeschooling program; and since then, pottery making has become a central part of Christian's life. He is now the owner of an enterprise by the name Christian Royal Pottery that makes hand-made stoneware. He sells his beautiful dishes and bowls online and at an art gallery in South Carolina.



Bernadette Resha



Hailing from Nashville, Tennessee, Bernadette is also an artist who has made a name for herself. Since an early age she was encouraged to use art as a means of expressing herself. She and her work have been featured on television shows, in music videos, commercials, and magazines. In addition to creating beautiful paintings, she is a public speaker and violinist as well. Bernadette recently married Josh, who also happens to have Down syndrome. The couple now lives independently and work in professions of their interest.

Michael Johnson

Michael is a gifted, self-taught and young Naïve Folk Artist. He has painted more than 500 commissioned portraits and had a solo exhibition at Vanderbilt University in 2001. His art has been featured in posters and on the cover of the American Journal of Public Health. He specializes in the paintings of animals and takes joy in painting portraits of pets for their owners.



Sujeet Desai



An accomplished musician, Sujeet has received his graduate degree from the Berkshire Hills Music Academy after a two year study in music and human services. He plays seven instruments including the violin, piano, trumpet and saxophone. He has received numerous awards and was even featured in the Wall Street Journal and Time Magazine as well as on 20/20 and the Oprah Winfrey Show. In 2006 he married Carolyn Bergeron who also has Down syndrome. He takes pride in the fact that he lives independently in an apartment in New York owned by himself.

Melissa Reilly

Melissa has accomplished quite a lot in her life. She has travelled the country as an inspirational speaker. She is a decorated, gold medal winning skier, cyclist, and swimmer and she has interned for a state senator. Melissa also teaches reading and math to preschoolers with Down syndrome. She says she loves her life 100%, and she proves that you can have a very fulfilling life with Down syndrome.



Through the achievements of these young individuals with Down syndrome the world is moving closer towards recognizing the fact that a certain genetic condition can in no means limit a person's ability to lead an inspiring and meaningful life. If provided with encouragement and support from the family and society, there is nothing individuals with Down syndrome can't achieve!

Source: www.lifenews.com

SPEAK OUT!

This section serves as a platform for parents, siblings and friends of individuals with Down syndrome to freely express their opinions, experiences, feelings and creativity. Speak out without any reservations!

My Daughter

My Daughter's name is Malhama Rizvi. When I came to know about her Down syndrome diagnosis, the first thought that came to my mind was that being a parent to a child with Down syndrome will be difficult. But with the passage of time, I have come to believe that it is both a blessing and a test by God. I hope I am successful at nurturing my daughter in the best manner possible!



Written by Aliya Hasnain, Mother of Malhama Rizvi

Calling Resource Teachers:

Sara Ahmed is a two year old child who is starting school at the Learning Tree from August 2016. If you are interested in supporting Sara by accompanying her to school and helping her, please do get in touch. If you have any further queries regarding this opportunity please contact KDSP on 021-34395377 or 0334-3355377. This is your chance to make a difference by contributing your time to helping a child learn and grow. Do get in touch if you feel you have the ability to do this job.

My Sister, Fareeha

Although Fareeha is my sister, she is just like a daughter to me. Before I got married, I helped my mother take care of Fareeha. Fareeha is very sweet and loves the going to the beach. She also loves dancing to her favourite songs. Sometimes she pretends to be a teacher and makes us learn poems and do other school tasks. I have no words to explain my love for my sister. Despite their illness, both my parents put in immense energy and effort to look after my loving sister.

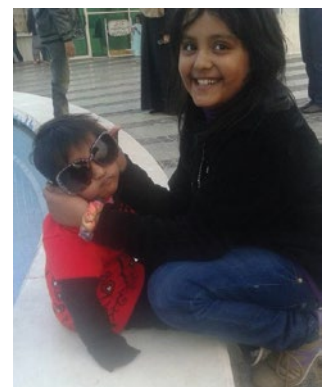


Written by Ayesha Zeeshan, sister of Fareeha.

Extra Cute!



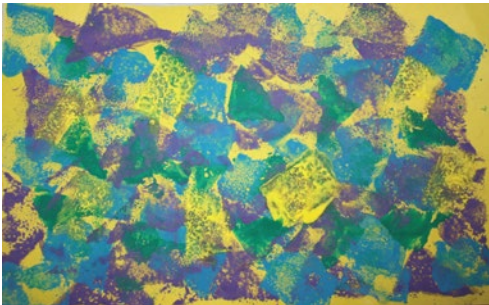
Ibrahim Ali,
4 years



Fasiha Farhan

COLOR SPLASH

BORN THIS WAY!



Emaan Khan, 6 years



Emaan Khan, 6 years



Nawal Fatima, 6 years



Born this way is a new, one of its kind reality TV show produced by A&E aired in 2015. The show comprised of 6 episodes, each lasting for an hour and documenting the routine lives of seven individuals with Down syndrome.

The cast members all had distinct personalities and different levels of abilities - the unpredictable, energetic and outspoken Elena; Cristina, the hopeless romantic with a passion for cooking; John, an entertainer who uses music and writing as a means of his expression; Megan, who owns a clothing business and aspires to become a film producer; Sean, a golf buff and a true ladies' man and Steve who has a rare form of Down syndrome called mosaic Down syndrome. The show highlighted their ambitions, career goals, hobbies and provided a chance for each individual to speak for themselves.

By treating the cast of Born This Way in much the same way they would treat any reality-show participants, the producers avoided any kind of condescending or patronizing tone. According to an A&E spokeswoman, "The series arose from the passion of executive producer Jon Murray, who has worked tirelessly to put a spotlight on people who have not been featured prominently in television or movies."

Born this Way also shed light on the families of the individuals and how they managed or felt about the challenges their children face, while trying to help them live as independent and satisfied individuals.

Viewers in Pakistan can easily access the episodes of this show on A&E TV's official website. Owing to the overwhelming positive response the show producers received, the second season of the show is in the pipeline. Do lookout for it!

Source: www.forbes.com and america.aljazeera.com

VOLUNTEER SPOTLIGHT

My name is Ruttaba Ahmed and I have completed my Masters in Special Education for Karachi University. I got to know about KDSP through a seminar on special needs held at Karachi University. I have been volunteering at KDSP since almost a year now. I have participated as a volunteer in various events and activities such as the Family Support Group sessions and trips to Kidz Dunya. I have had a superb experience while volunteering and have learnt a lot through interaction with children with Down syndrome, including how to effectively handle them.

Ruttaba Ahmed, Masters in Special Education from Karachi University. Currently works at Paradise Special School Centre.

ACTIVITIES AT KDSP

Arts and Crafts for Adults - October 2015

In consideration of the Down syndrome Awareness month, our very talented arts and crafts participants also made use materials in blue and yellow colour to adroitly craft lovely stuffed toy ducks and strawberry key chains. The colours blue and yellow were picked because they officially represent Down syndrome.



October - Down Syndrome Awareness Month

KDSP celebrated the Down Syndrome Awareness Month throughout October. The KDSP office was decorated in blue and yellow streamers and balloons to represent Down syndrome. An awareness campaign was launched through the platform of social media which aimed to debunk common misconceptions about Down syndrome.

Dessert Time with Sugar Shack

The little chefs were busy making oreo balls during dessert time with Sugar Shack held on October 03, 2015. Every participant had a wonderful time crushing oreos, kneading them with cream cheese and milk, rolling the batter into balls. In the end they decorated their oreo balls with MnMs and crushed coconuts, and were ready to take them home as a snack-time munch.



Family Support Group Session 14

The 14th FSG Session was held on October 31, 2015 on “Skin Care Needs of Individuals with Down syndrome.” The speaker for this session was Dr. Saadia Tabassum, Consultant Dermatologist and Assistant Professor in the Department of Medicine, Aga Khan University Hospital. This informative session was attended by 20 parents and caregivers.

Workshop on Reading Skills

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



Family Support Group Session 15

The 15th FSG session was held on November 21, 2015 in which Dr. Babar led the discussion on cardiac issues faced by individuals. The session was attended by 35 parents and care-givers. Dr Babar is a Paediatric Cardiac Health Specialist at the Department of Paediatrics and Child Health at the Aga Khan university hospital, Karachi.

Arts and Crafts for Adults - November 2015

During November, our weekly arts and crafts participants intricately crafted stuffed strawberry keychains and ducks in continuation of the stuffed stitching module introduced earlier in October. In addition, the also made mobile covers in several appealing designs.



HEALTH AND DEVELOPMENT

Oral Health Care for Individuals with Down syndrome

Establishing good dental habits including getting your child used to the dental environment at an early age can reduce the likelihood of dental problems in the future. People with Down syndrome have no unique oral health problems and are prone to the same degree of dental disease as the general population. However, some of the problems they have tend to be more common in people with Down's syndrome.

Children with Down syndrome may have delayed development of the teeth and jaw with the first (baby) teeth not appearing until the age of two and it may take another two to three years for them all to be present. Similarly the eruption of the permanent (adult) teeth may be delayed with baby teeth still being present at fourteen years; teeth may also present in an unusual order. It is very common for some of the baby and adult teeth to be missing, and for teeth to be smaller than normal.

Individuals with Down syndrome have are commonly faced with the issue of gum disease (periodontal disease) This is because people with Down syndrome have an impaired immune system and do not have some of the natural protections against the disease as people without Down syndrome have. In some cases, the gum disease experienced can be aggressive, where permanent front teeth can be lost while the young person is in their teenage years.

Often the tongue appears to protrude from the mouth, usually due to the mouth being smaller than normal and less able to accommodate it. This can make it more difficult to clean the teeth because the tongue gets in the way.

Here are some tips to ensure optimal oral health care:

- Avoid sugar in foods, snacks and treats as much as possible.
- Some people with Down syndrome can brush and floss independently, but many need help. A power toothbrush or a floss holder can simplify oral care. Regular visits to a dentist.
- Consider topical fluoride, fluoride varnish and sealants.
- Brush, rinse, floss and/or apply dental agents according to the dentist's instructions. Some children will need to have oral care several times each day.
- Desensitize children at home so oral care seems like a normal part of life. Talk about going to the dentist and show them what the dentist will do. Picture books or homemade experience books are also an excellent way to help children understand what will happen once they get to the dentist.
- Build trust and take it slow. Make the first several attempts positive to gain more cooperation later on.
- Give lots of positive feedback to reinforce good behavior.

Early professional treatment and daily care at home can mitigate their severity and allow people with Down syndrome to enjoy the benefits of a healthy mouth.

Source: www.downsyndrome.org.uk, www.ndss.com and Down's Syndrome Association's Publication: A Guide for Parents and Carers

MAKE THIS NEWSLETTER TRULY YOURS!

Own the KDSP newsletter by sending us articles, information, news, your experience or art work, stories, poems and photographs of your children or siblings. KDSP will be more than happy to share your contributions with the Down Syndrome advocates and supporters all across Karachi!

Send your contributions to publications@kdsp.org.pk



Karachi Down Syndrome Program

Karachi Down Syndrome Program

Suite 102, First floor, Jason Trade Centre
Main Shahra-e-Faisal, Karachi.
Phone: 021-34315377 or 34385377
Email: info@kdsp.org.pk
www.kdsp.org.pk

Find us on Facebook:
<https://www.facebook.com/kdsprogram>

Find us on LinkedIn:
<https://www.linkedin.com/company/karachidown-syndrome-program>