Karachi Down Syndrome Program

KDSP's quarterly newsletter

A Little Extra

Volume 7 Issue 1 Q1 2020

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

Q1 2020
Impact Statistics

- 67 new families registered
- 2 Family Support Group sessions held
- 14 new enrolments in the Early Preschool Experience Program (EPEP)
- 5 new enrolments in the Tailored Assistance Program (TAP)
- 15 members benefited from the Program for Inclusive Education (PIE)
- 300+ Early Childhood Intervention (ECI) therapy sessions conducted per week
- 5,500 attendees at the KDSP Carnival 2020
- 6.800 hearts touched though our World Down Syndrome Day Campaign
- 39 children referred to AKUH & TIH
- 4 lifesaving medical procedures performed
- 16 children enrolled in skill development activities
- 10 adults enrolled in enrichment programs

Healthcare

Friday, 3 January 2020

Dental Camp

KDSP organized a free of cost dental camp for individuals with Down syndrome in collaboration with a team of internationally trained dentists.

A total of 37 individuals were examined during the day-long camp by a team of 6 dentists, including **Dr. Saif Khan, Dr. Aneeka Anwar, Dr. Ayesha Arif, Dr. Samar Sultan, Dr. Sadaf Jamal** and **Ms. Ammarah Nauman**.

Parents and caregivers were counseled on how to maintain good oral hygiene for their child with Down syndrome.

Saturday, 18 January 2020

ICON 2020

KDSP hosted a symposium titled '**Down Syndrome In Focus: Bridging the Gap Between Practitioner Knowledge and Individual Realities**' at ICON 2020 - The Indus Hospital's 5th Biennial Conference.

KDSP was successful in bringing conference delegates, medical practitioners and families of individuals with Down syndrome a little closer to understanding Down syndrome from a new perspective in the 21st century.

Life-Saving Surgeries

KDSP sponsors and facilitates essential medical procedures for people with Down syndrome

Sarah Mazari, age 4 years
Sarah had previously undergone a surgical procedure called posterior sagittal anorectoplasty (PSARP) to correct her diagnosed health condition, "imperforate anus" on 18 July 2019. The final step of her procedure was a reversal of colostomy, whereby in January 2020 Dr. Sohail led the operation to close the hole in her abdomen.

Abdul Haseeb, age 6 years
It had been discovered that Abdul Haseeb's tonsils were bleeding internally. KDSP facilitated his surgery in March 2020, after which he is now able to partake in and enjoy his daily activities.

Early Childhood Intervention

Developmental Pediatrics Consulting Clinic

KDSP recently hosted the third round of its ongoing **Developmental Pediatrics Consulting Clinic** for individuals with Down syndrome aged between 0-18 years old. The clinic was conducted by developmental pediatrician **Dr. Sidra Kaleem Jafri** with the aim of ascertaining the developmental status of these individuals.

Dr. Sidra Kaleem Jafri worked as a Senior Fellow at the Aga Khan University Hospital Department of Pediatrics and Child Health and has recently resumed her clinics at KDSP after completing her Masters from McMaster University in Developmental Pediatrics.

Family Support

Two monthly Family Support Group sessions were conducted to empower parents and caregivers with meaningful information for the care of their loved ones with Down syndrome.

- **Importance of Occupational Therapy for Children with Down Syndrome** presented by Ms. Najma Adam, Head of Occupational Therapy at KDSP.
- **Cardiac Care for Individuals with Down Syndrome** presented by Dr. Fatima Ali, Pediatric Cardiologist at the Aga Khan University Hospital (AKUH)'s Department of Pediatrics and Child Health.

Monday, 3 February 2020

Drawing Our Dreams

As mothers invest their time and energies in taking care of their children, they often forget to take care of themselves. Making time to relax, recharge and address your own needs is essential as a parent. A contented mother raises a contented child!

KDSP hosted "**Drawing our Dreams**", a session that took 9 mothers on a journey of self-exploration and self-care through the medium of art. The session was facilitated by **Farzeen Ali**, Co-Founder and CEO at KDSP who is also an Art in Therapy Practitioner.

Education and Training

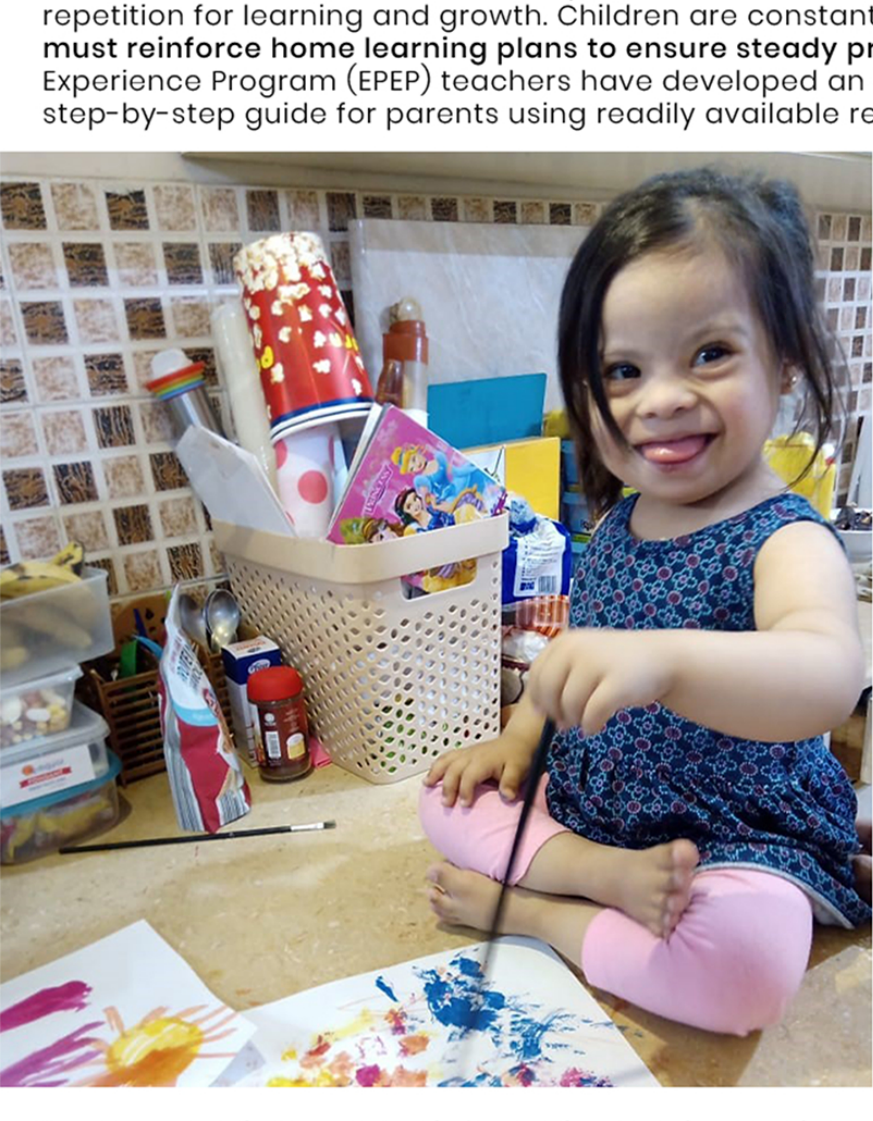
Thursday, 13 February 2020

Career Day

Teachers of the **Tailored Assistance Program** (**TAP**) organized a **Career Day** for students followed by a donut party. Students enthusiastically dressed up according to their favorite professions – we saw doctors, teachers, chefs, business owners and even an army officer! It was an exciting chance for students to interactively explore their field of interest as an extension of the academic and life skills program.

10 Quick Tips for Home Schooling

As teachers of children with Down syndrome, we are acutely aware of the importance of reinforcement and repetition for learning and growth. Children are constantly learning from their surroundings therefore **parents must reinforce home learning plans to ensure steady progress and development**. Our Early Preschool Experience Program (EPEP) teachers have developed an extensive homeschool plan for students with a step-by-step guide for parents using readily available resources at home.



Below are 10 quick tips for home-schooling parents:

1. **Build a routine.** A fixed schedule is conducive to the child's learning.
2. **Identify how your child learns.** All children learn differently; figure out how your child learns, what motivates them and what their strengths are.
3. **Wait 10 seconds.** After a request has been made, allow 10 seconds of wait time before expecting a response. Interrupting the processing time short circuits their thinking and can lead to frustration.
4. **Incorporate and encourage total communication.** Throughout all daily activities, use and accept auditory, gestural and visual forms of communication.
5. **Use visual cues and schedules.** Most students with Down syndrome are strong visual learners; capitalize on and reinforce information with this strength.
6. **Avoid closed questions.** Encourage more than one word utterances by allowing your child the freedom to express themselves.
7. **Ensure you are face-to-face with good eye contact when giving directions.** This will help your child take cues from your facial expressions.
8. **Ask your child to repeat information and instructions back to you.** This gives your child an opportunity to participate in the conversation, rather than it being one sided.
9. **Use simple and familiar language.** Stay just one step ahead of the child's level.
10. **Be patient.** Your child's receptive language skills may be more advanced than their expressive language skills. Give them time to respond and pay attention to their body language. Children have more than one way to communicate.

Enrichment Programs

Ongoing Activities @KDSP

NEW YEAR'S HI TEA: An exciting get-together was held at KDSP on 11 January 2020 to celebrate the new year. Hi-tea was arranged for families to unwind, with scrumptious **doughnuts sent in by EASY**, while families mingled and had a great time!

CREATIVE EXPRESSION: In collaboration with artist Safwan Subzwari, KDSP held a "**Creative Expression Workshop**" on 25 January 2020, where students from the Tailored Assistance Program (TAP) experimented with color palettes and created a beautiful mural.

WEAVING: Ms. Imrana Shahryar from **Indus Valley School of Art and Architecture (IVS)** visited KDSP on 21 February 2020 to distribute certificates to participants with Down syndrome for successfully completing an 8 week course on '**Introduction to Weaving**' at IVS.

TDF MagnifiScience: On 15 January 2020, KDSP arranged a field visit to **The Dawood Foundation (TDF) - MagnifiScience Children's Studio**, a specially curated space for children to explore science, mathematics, technology and illusions with fun hands-on activities and exhibits.

New Programs @KDSP

CLAY ART: In collaboration with **Mudpie Studio**, participants use clay as a medium to express themselves and explore the possibilities of all they can create.

BLOCK & SCREEN PRINT: The program aims to teach individuals with Down syndrome the basics of block & screen printing, in turn expanding their range of abilities and interests.

TEDDY TENNIS: In collaboration with **Teddy Tennis** Pakistan, KDSP hopes to inspire children with Down syndrome to learn and excel at tennis.

WONDER GAMES: Specially designed for children with special needs, the program aims to improve motor, functional and cognitive skills of individuals with Down syndrome by utilizing augmented reality games.

Awareness

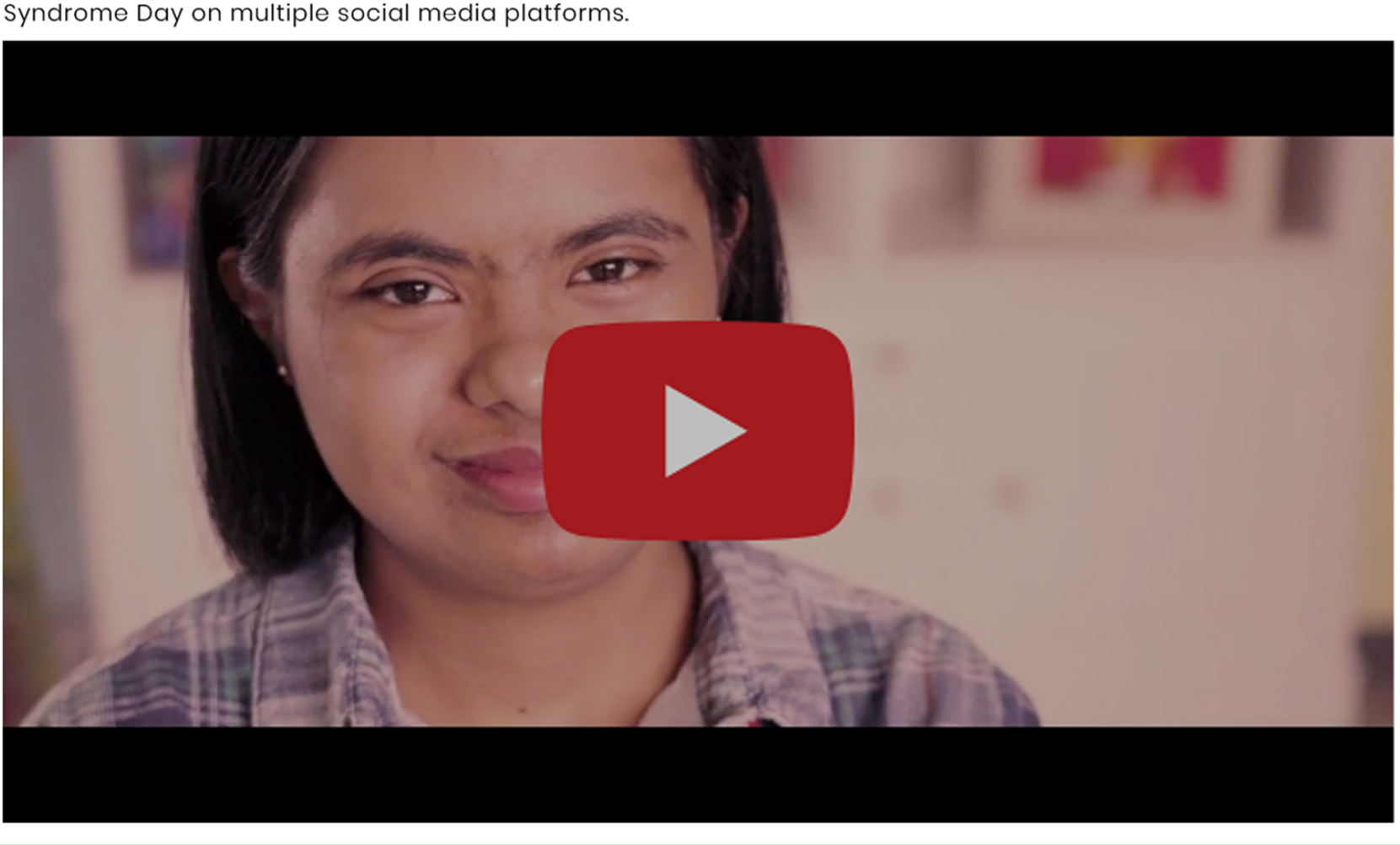
World Down Syndrome Day Campaign

SOUL FEST: KDSP participated in Soul Fest, exhibiting unique crafter's products made by our very own individuals with Down syndrome, which sold out rapidly.

GUIDED TOURS: Mommy bloggers, influencers, publications and editors were invited to KDSP for a guided tour and to gain firsthand knowledge of Down syndrome.

ACTIVATION: KDSP's stall at Dolmen Mall Clifton in partnership with Dolmen Cares & Everblocks which featured a selfie booth, a giant Lego throne and our crafters' products, drew 300+ people.

DOWN SYNDROME AWARENESS VIDEO: Ali Hamza, Shafaat Ali, Mariam Nafees, Rabab Hashim and Hassan Rizvi were amongst the many celebrities who helped launch our new awareness video in celebration of World Down Syndrome Day on multiple social media platforms.



KDSP Carnival 2020

On Sunday, 16 February 2020 KDSP successfully concluded its **6th Annual Carnival** in celebration of World Down Syndrome Day. Through the years, the event has established itself as a platform that fosters inclusion and acceptance in society. Over 5,500 people of all ages and abilities participated in meaningful games and activities while indulging in a variety of food and crafts.

This edition of the Carnival witnessed the launch of '**Kahani Ghar**', a dedicated story space to bring every child's imagination to life. The talented Khaled Anam wove a story through music, Chimpu dared to be different in a play organized by Shehzad Ghias, young individuals braved the world to find a lost calf in a story by Azcorp Entertainment and the truth was unveiled behind the conniving Vazir and an arrogant Raja in a captivating story enactment by Zambeel Dramatic Readings.

Click here for more carnival highlights

KDSP CARNIVAL 2020

We would like to thank all of our esteemed partners

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Employee Engagement @ KDSP

Trainer and life coach Mr. Sohail Zindani delivered a **Family Network Relations training** to KDSP employees. The session was both insightful and thought-provoking, leaving the attendees with the know-how to communicate effectively with colleagues, Family Network members and other external stakeholders.

On a separate occasion, in response to the rapid spread outbreak of COVID-19, KDSP held a special healthcare session for its employees conducted by Dr. Syed Rehan Amin to educate the team about the virus and the correct safety precautions to follow.

Working in the age of COVID-19

KDSP has proactively mobilized its team and resources to provide services through alternate channels in compliance with the social distancing guidelines, while also striving to maintain the same level of productivity and enthusiasm in these uncertain times.

We are regularly monitoring the government's updates regarding COVID-19 and it is prudent to assume that the 'home office' will be a mainstay for some time to come. To ensure our operations run seamlessly and all crucial information is available and accessible to our stakeholders, we have taken the following steps:

- KDSP's landline, cellphone and email are fully operational, allowing information seekers to make contact with ease
- Our Early Childhood Intervention team is offering therapies as per schedule through voice and video calls
- Our Education & Training team is creating home-based activity plans for students and helping parents implement them
- Our Enrichment & Skills Development team is creating flexible new programs for members and their families
- Our Family Support team is virtually addressing the needs and concerns of families
- Our Awareness team is using social media platforms to update our audience on relevant information

Parent's Corner

Dear KDSP,

On 2nd August 2017, I gave birth to a girl, Silah, who was born with Down syndrome. After discovering KDSP, my husband and I were in awe at the selflessness and devotion of the people here. My first thought was perhaps it is all a façade for parents that visit, but as we got to know the organization more, we realized we were so wrong. There was no façade; the empathy, concern and care we received from each department was 100% genuine.

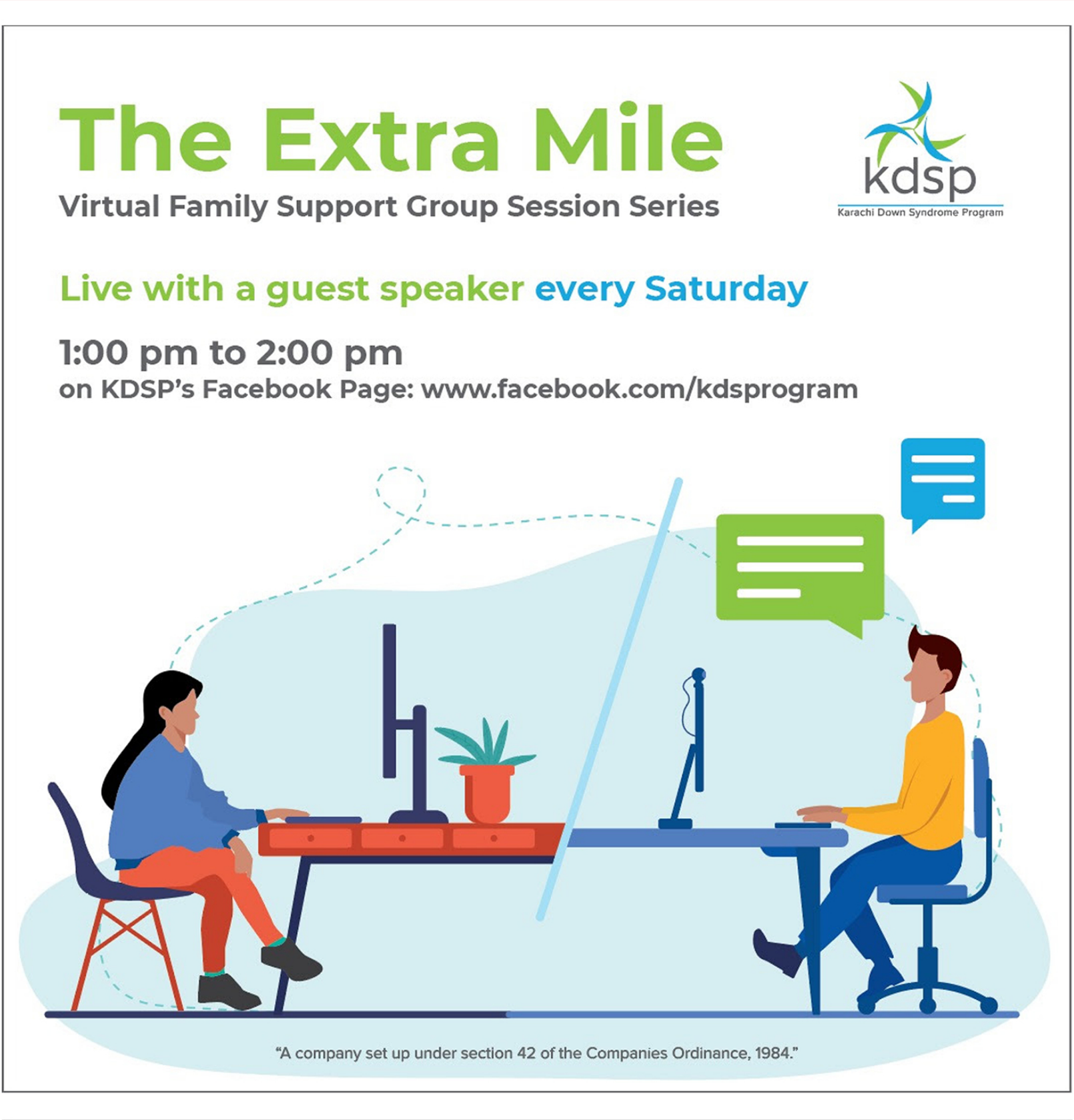
My daughter started receiving Early Childhood Intervention therapies when she was 1.5 months old. From the get-go, our daughter was provided with highly competent therapists, an empathetic environment, and detailed home-learning plans, while my husband and I received immense support from the family group sessions.

When she was older, Silah was enrolled in the Early Preschool Experience Program (EPEP). Even though she wasn't able to take regular classes, the teachers never made her feel left out. They consistently provided us with home-learning plans, so our daughter could be at par with her classmates whenever she returned.

KDSP shares the credit of everything my daughter has achieved. She has come so far because of the team effort of everyone at KDSP and us, her parents.

– Talkhlees Adil
A mother who, after Allah SWT, relies completely on KDSP for my daughter's bright future

Upcoming Events @ KDSP



The Extra Mile
Virtual Family Support Group Session Series

Live with a guest speaker every Saturday

1:00 pm to 2:00 pm
on KDSP's Facebook Page: www.facebook.com/kdsprogram

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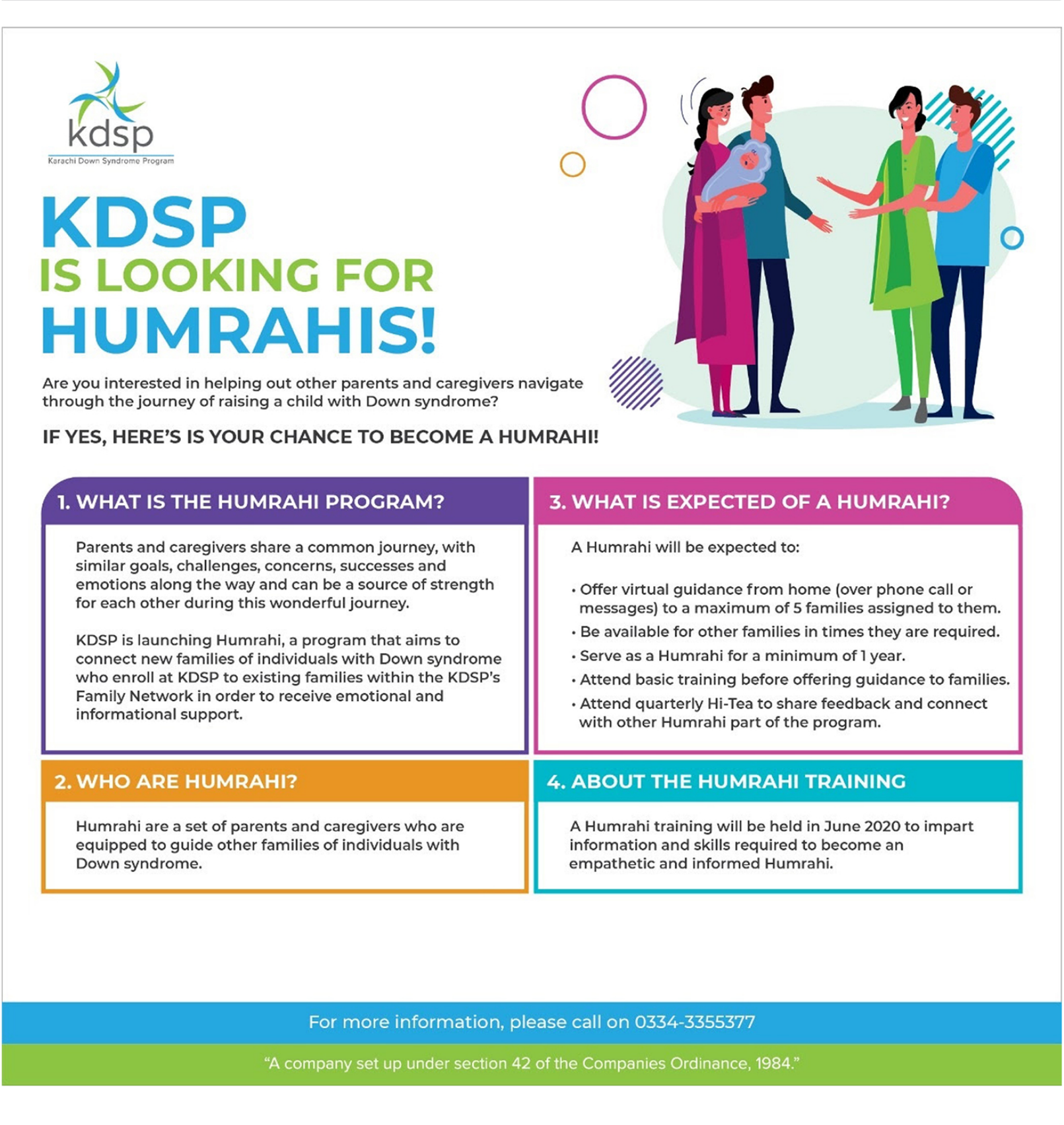

KDSP IS LOOKING FOR HUMRAHIS!

Are you interested in helping out other parents and caregivers navigate through the journey of raising a child with Down syndrome?

IF YES, HERE'S IS YOUR CHANCE TO BECOME A HUMRAHI!

1. WHAT IS THE HUMRAHI PROGRAM?

Parents and caregivers share a common journey, with similar goals, challenges, concerns, successes and emotions along the way and can be a source of strength for each other during this wonderful journey.

KDSP is launching Humrahi, a program that aims to connect new families of individuals with Down syndrome who enroll at KDSP to existing families within the KDSP's Family Network in order to receive emotional and informational support.

2. WHO ARE HUMRAHI?

Humrahi are a set of parents and caregivers who are equipped to guide other families of individuals with Down syndrome.

3. WHAT IS EXPECTED OF A HUMRAHI?

A Humrahi will be expected to:

- Offer virtual guidance from home (over phone call or messages) to a maximum of 5 families assigned to them.
- Be available for other families in times they are required.
- Serve as a Humrahi for a minimum of 1 year.
- Attend basic training before offering guidance to families.
- Attend quarterly Hi-Tea to share feedback and connect with other Humrahi part of the program.

4. ABOUT THE HUMRAHI TRAINING

A Humrahi training will be held in June 2020 to impart information and skills required to become an empathetic and informed Humrahi.

For more information, please call on 0334-3355377

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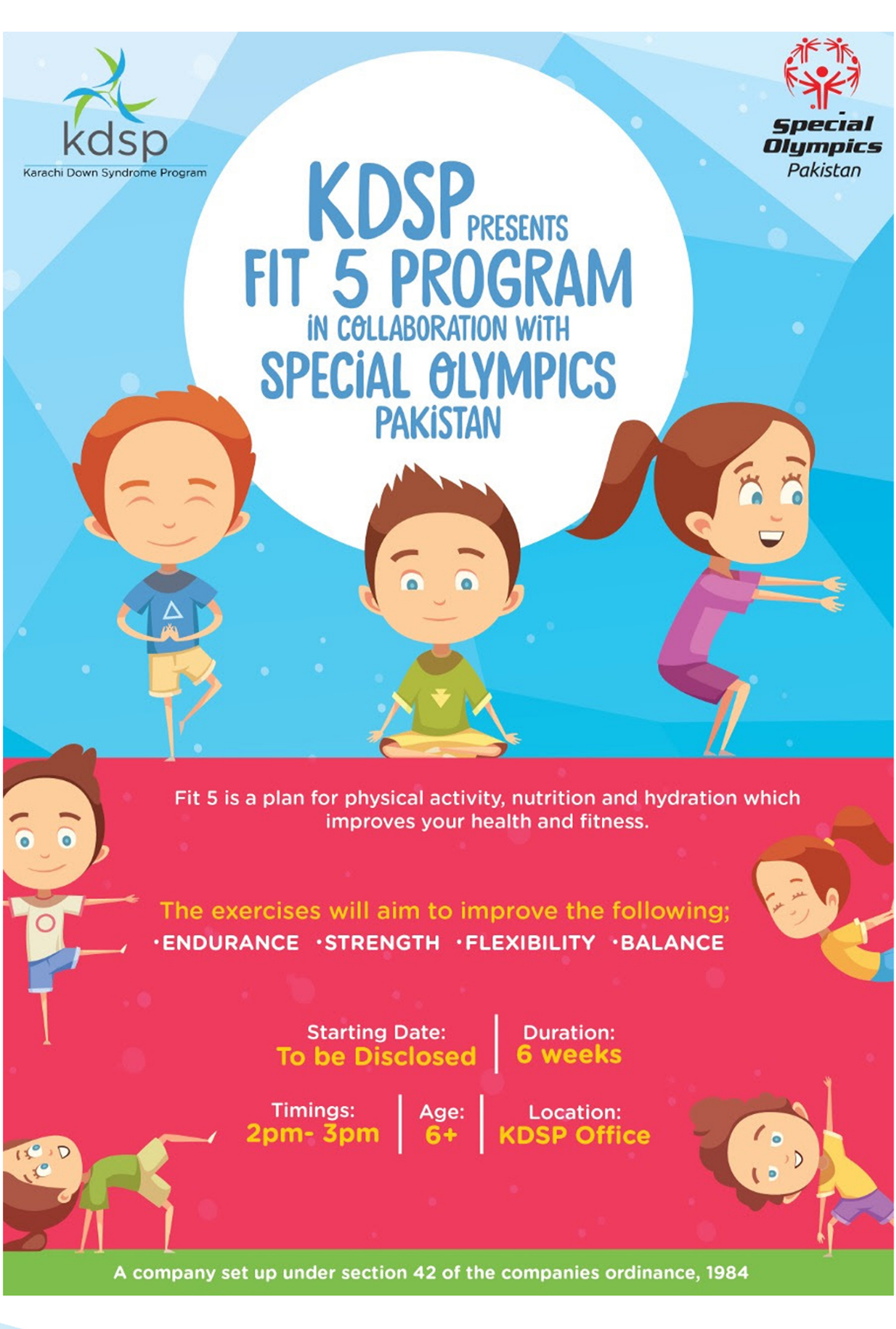

Special Olympics Pakistan

KDSP PRESENTS FIT 5 PROGRAM IN COLLABORATION WITH SPECIAL OLYMPICS PAKISTAN

Fit 5 is a plan for physical activity, nutrition and hydration which improves your health and fitness.

The exercises will aim to improve the following;
- ENDURANCE
- STRENGTH
- FLEXIBILITY
- BALANCE

Starting Date: To be Disclosed
Duration: 6 weeks
Timings: 2pm- 3pm
Age: 6+
Location: KDSP Office

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KDSP wishes to thank TCS for its support and efficiency in always helping us through our endeavors

TCS WE MOVE YOU

Let's make a difference in the lives of individuals with Down syndrome together. Your zakat and donation can help us ensure no one is ever left behind!

Donate Now

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To know more:
Call 021-34315377, 021-34395377, 0334-3355377 or email info@kdsp.org.pk

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