SPOTLIGHT
Family Resource Center at Ummeed

It gives us great pleasure to share that the Family Resource Center (FRC) has a dedicated physical space at the Ummeed center – a space ‘for families and by families’ – for all families to connect with each other, seek any kind of support, access opportunities for fun and leisure and take the lead in guiding and supporting other families.

The FRC team comprises of parents of children with disabilities, our hope is to make Family Resource Center a hub for support, information, fun and community. We intend to organize hobby sessions, family get-togethers, informative talks and other such programs at the Family Resource Center.

If you are a parent of a child with disability or are a person with disability yourself, and are interested in volunteering at the FRC, please connect with us at frc@ummeed.org or 8591850804.

We invite all families to participate in the activities and events of the Family Resource Center from April 2023 onwards.

JUST A FEW PRECIOUS SECONDS
SANGEETHA CHAKRAPANI

Do you remember that moment in school when you could not say the right answer immediately? Before you could try one more time, the teacher patted you kindly on the shoulder- Never mind, next time ok? The frustration - I needed only 1 minute more!! This is what happens frequently with many people with autism and their families.

Read More on Page 6

CREATIVE CORNER
Nehal (22 years) finds language and communication a bit challenging but loves expressing herself through her art.

Read More on Page 5

MY STORY
Ruchi Patil is mother to 19-year-old Arijee, who is 100% visually impaired. Arijee recently graduated from school and got outstanding scores in the International Baccalaureate (IB) Diploma program. In this heartfelt piece, Ruchi describes how she moved from a state of guilt and sorrow to one of acceptance and support of Arijee’s disability. Read Ruchi’s story in her own words.

Read More on Page 2

THE 55 KM WALK FOR UMMEED

Every year in January, UMMEED hosts its annual fundraising event, the “55 Km Walk for UMMEED”

Read More on Page 8
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The Early Years

Arijit was a premature child. I felt really guilty for not being able to keep him full term, or not reaching hospital earlier & availing care that could have averted this premature delivery. I was still reeling under this guilt, when his eyes started showing signs of being affected by prematurity. As a 1-month-old new-born, he had to get laser procedures with his eyes clipped with steel clips. I couldn’t see him suffer - he would howl inside, and I outside; of course for his pain, but more out of guilt and regret.

When lasers could do no more, came his eye surgeries and the downward graph on his vision - which we were losing steadily despite all efforts through 4 surgeries over 2 years. I was faced with the fear of dealing with a disability in my child. I was hoping for an exit route out of the situation, but there were none. The only thing I had was unconditional love in my hands, and so I spent every waking moment caring for him, just the way I was asked, by doctors and therapists. I couldn’t lose any more - there was a lot at stake and it all depended on me.

The Journey Begins

Other kids learn so much about the world by looking at what is around them. I knew I had to show Arijit the world through his ears. So, I filled his life with music - I played happy music, prayerful music for him, I spoke to him endlessly, sang rhymes. I learnt physiotherapy and put it to practice every single day. Thankfully he started walking at 15 months of age.
The School Years

Arijeet was school ready, and we were advised he’s a bright kid and must go to a mainstream school. We too agreed because he could go to a special school and college but there was no special world - he had to live here. But how would his education work - no one knew - not the schools & not us. We worked closely with the schools towards integrating him into the school program, giving all the support that was needed, in terms of teaching aids, techniques, systems, teaching support at home and shadow teacher. We worked on one goal, one class, one teacher at a time. The school’s support made it possible.

The next step after integration was inclusion and with our efforts it was happening slowly. I wanted his inclusion with dignity and that was happening with the school’s open mindset, the sensitisation workshops we conducted, the teachers’ modelling of positive behaviours and appreciating the children who were helping.

I didn’t want him to be alone, doing nothing and think of his disability, I wanted him to build a lot of ability before he knew of his disability. And as we were both working towards this goal - a lot of times I found Arijeet ahead of me – lapping up everything I could give, at a faster pace. I am deeply indebted to the guidance of Dr Vibha Krishnamurthy, Dr Raju Khubchandani and Mrs Sheela Sinha who were constantly guiding me towards this.

I reminded myself day in and day out, I must see my child for what he can do and not for what he can’t and slowly fill that basket.

The school gave him every opportunity, equal and more, with participation at every act, event and giving him the platform to build his skills and confidence.

The parents and children were reinforcing his efforts with their applause and comments. The way inclusion or Arijeet’s schooling happened, seemed like a dream come true. I think it could be a model that could be followed. Ms Jamali’s
(Principal – Beacon High School) words still ring in my ears, "I want him to walk out of my school, a young confident man." And he did. Arijeeet’s words ring too, I remember him say one day, "See what you can do for your school and not what your school can do for you".
And he did, we had named his dream ‘Vision 2020’ and the culmination of that dream was the outstanding results that Arijeeet achieved. It was truly a testament to all the hard work put in by him and the support the system offered.

He was the first blind student to do ICSE with Maths and Science and having secured a 96 percent overall with a 99 in maths.

He then got admitted into Bombay International School on merit and completed the very intense IBDP curriculum with the support he received again from Dr Cyrus Vakil, Ms Priyamvada Das and other teachers. He achieved outstanding results in his IBDP exams. He had his challenges with inclusion though, as most of his tenure at BIS happened during COVID times – with online schooling. Yet, he made some lovely friends, went for the school prom with a partner and did a trip with the students to Goa.

THE JOURNEY AHEAD
While we have come a long way, we certainly have a long way to go. But I have the faith, as his journey was supported this far, he shall be guided and guarded in the future as well. He plans to pursue his undergraduate education in public policy and computer science.

Visually impaired Arijeeet outperforms at International Baccalaureate Diploma exam

Nafisa Kharoca | Posted on Thursday, December 8, 2022 17:03

Mumbai boy aims to build a career centred on the delivery of affordable assistive technologies, and services to help people with disabilities

Mumbai boy Arijeeet Patil suffering from 100% visual impairment got outstanding scores in the International Baccalaureate (IB) Diploma Program in the May 2022 examination. By achieving the top scores Arijeeet shattered the stereotypes associated with differently-abled students.

Arijeeet was admitted to the Bombay International School (BIS) in Mumbai in 2020. Joining the IB Diploma Program, in the middle of the pandemic restricted physical interaction with teachers and classmates. Despite the

Read Arijeeet’s inspiring story that was featured in the newspaper.
“Everyone has a mountain to climb but Autism has not been my mountain, it has been my opportunity for victory.”

Nehal (22 years) finds language and communication a bit challenging but loves expressing herself through her art. She currently works at EY as an Associate Consultant and also has a special talent in stone painting. She loves to paint on stones in various styles. She has delivered more than 1000 orders of stone painting and displayed them at exhibitions as well.

Nehal’s work can be viewed at https://stonepainting-nehal.com and on Instagram https://instagram.com/stonepainting.mumbai
The sweetest of smiles breaks out on Rohit’s face equivalent to a hundred Hellos
Or
Rohit extends a hand tentatively
Or
Rohit says a Hi that is just about audible but sounds like sweet music to the mother.
Or
Rohit is looking deep into the Milky Way but says a loud Hi
Or
Rohit looks straight into Sheena’s eyes and says a crisp Hi
Or
Rohit just glances at Sheena - one more way of saying Hi!!

Pause Pause Pause Pause for a few precious, precious seconds, and then……

Wow- imagine meeting you here! Hello! HI! How are you doing?

Sheena : Hello Rohit

Mom : Rohit, Let’s say Hi to Sheena
Sheena : I also like talking with you Rohit!

Sangeetha is parent to quadruplets – 2 of whom are neurotypical and 2 of whom have autism. She shares an example of how we can all enable greater participation of neuro-diverse individuals.

Do you remember that moment in school when you could not say the right answer immediately? Before you could try one more time, the teacher patted you kindly on the shoulder- Never mind, next time ok? The frustration - I needed only 1 minute more !!

This is what happens frequently with many people with autism and their families.

Picture this: A family is out with their son Rohit who has autism. They meet a good friend.

Mom : Rohit, look who’s here? Sheena!
Sheena : Hi Rohit
Mom : Rohit, say Hello to Sheena
Sheena : Hi Rohit, Hi!
Dad : Rohit, Sheena is saying Hi to you
Sheena : It’s okay! Pats Rohit on head or shoulder.

Wow! What a surprise to see all of you here! Big round of Hellos follows.

Big round of Byes are exchanged

In all this melee of conversation, Rohit did not get a chance to say Hello and Sheena did not get a chance to connect with Rohit.
This simple exchange of greetings is so important for people with autism. To be given the time and the opportunity to process that:

1. Somebody known to them has suddenly come up.
2. To process the identity of that person.
3. To process the greeting that person is making.
4. To process the suggestion made by the mother.
5. To convert it into an action

It is not kind to shush a person with autism when he is trying to say or signal something.

It is not kind to pat him on the head and move away.

It is not kind to expect him to respond instantaneously.

It is not kind to bombard him with multiple instructions – Say Hi, Come on, Quickly say Hi, Chalo Hi bolo.

It is being kind when you make an effort to look into Rohit’s eyes, greet him and give him a few seconds of quiet time to acknowledge you.

Be THAT person in Rohit’s life who opens gateways of communication with him by gifting him a few seconds of your time and your acceptance.

Sangeetha is the co-founder of Together foundation. Together Foundation currently runs several employment and pre-employment courses for adults with disabilities. ‘Together Community’ is their new initiative, which is a residential project in Bangalore, for people with autism & special needs and their families. Find out more about Together Foundation on https://togetherfoundatontrust.org
Every year in January, UMMEED hosts its annual fundraising event, the “55 Km Walk for UMMEED” in Goa. It also provides us the opportunity to create awareness about developmental disabilities and showcase UMMEED’s work.

This year, the event was held in its full glory after 2 years on 21st January 2023. A total of 79 walkers participated in the walk, out of which 20 completed the full 55 km, while the rest completed between 10 and 55 km.

But the Walk is more than just the distance people cover. For our Walkers over the past many years, the Walk has meant a variety of things – great company, feeling fit, doing something for a good cause, meeting like-minded people, feeling empowered, etc. The route for the Walk is along one of the loveliest beaches in the world, with an early morning start and a gorgeous sunrise, and the final stretch of ends with an amazing sunset, pleasant temperatures, and a huge sense of achievement.

The walkers are a diverse group of fitness enthusiasts, friends & supporters of Ummeed, Ummeed families, and of course Ummeed employees. The funds raised by these walkers are used to incubate new projects at UMMEED. UMMEED would like to express its gratitude for the support received from all the walkers and their donors.

Did you enjoy reading this newsletter?
We would love to hear from you and welcome your feedback, comments, suggestions and ideas.
Please write to us at frc@ummeed.org or send us a message on 8591850804