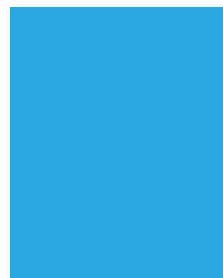




ANNUAL REPORT 2021 - 22



MESSAGE FROM THE MANAGING TRUSTEE



Dr. Sushama Nagarkar

Another year; another round of COVID-19 related anxieties. Fatiguing. Mind boggling. Keeping our team safe and healthy both mentally and physically as well as confident, happy is of utmost importance as it was during the first wave. And will continue to be the *raison d'être* for YCT.

The vaccinations were finally approved by the GOI and scheduled – but it was totally incomprehensible to us why persons with intellectual and developmental disabilities (PwIDD) – who we all know are at utmost risk of infection, were not listed in the priority groups for receiving the vaccine. We did the rounds of everyone we could contact: from the state health minister, the Municipal Commissioner, the local corporator, the head of the BMC health division. We sent follow up email after email, articles from reputed publications, a blitzkrieg on social media trying to drum up awareness and support for vaccinating PwIDD early and quickly. Our efforts all fell on deaf ears. Then the non-profit sector stepped in as we often do when the government fails to respond. A set of team members got their first dose through the well-coordinated efforts of Adventures Beyond Barriers Foundation (ABBF), a Pune-based non-profit organisation that promotes disability inclusion. As always, we are eternally grateful not only to ABBF, but to Niranjana Hiranandani and the Hiranandani Hospital for sponsoring some of our vaccinations. We raised funds and took care of the entire team of PwIDD, support staff and volunteers as quickly as possible. Having had their vaccinations was made a prerequisite to return to work. And there was no compromise on that.

After we were all vaccinated and ‘safe’, we regrouped and began to train and work in earnest. We continued, as had been suggested, to mask up as an added safety precaution. Our café began to function again in a small way with limited seating. We were far from being financially viable, but we were able to come to work and heaved a collective sigh of relief. Because for our team, work is truly worship.

As the city limped back to some semblance of normalcy, we began to hope and plan for better times. And the way forward. Trainees began to enrol at the SDC, our counselling caseloads, which had increased substantially during the pandemic, began to reduce for good reason – people were less isolated and lonely now – and we continued to focus on our advocacy work.

Our team of self-advocates successfully told their stories to groups of students in a few suburban schools and colleges. The feedback was very positive and more importantly they created an awareness of what life of a person with a significant disability was like. During the year we also took on a larger issue: one that has adversely impacted many families – that of the indiscriminate propagation of Stem Cell Therapy as a cure for autism. We simultaneously launched a qualitative research project around the topic as well as began work towards preparing a Public Interest Litigation in the Supreme Court. It will be a long road ahead.

COVID-19 taught us a lot. Importantly it taught us to value life and our relationships and make every moment count. And, at YCT, that is what we are doing. Every individual who is a part of our extended family counts and everything we continue to do to make our community more just, more equitable counts. At the end of the day, that is what truly matters.

HIGHLIGHTS OF OUR YEAR

The Yash Charitable Trust's team members received their first dose of the Covid-19 vaccine in May 2021 and the second in September 2021. We would like to thank the wonderful people at Adventures Beyond Barriers Foundation (ABBF), S.L. Raheja Hospital, Mr. Niranjana Hiranandani and the generous team at L.H. Hiranandani Hospital in Powai for including us at their vaccine drives.



A focus area for YCT has been on propagating evidence-based practices towards the betterment of lives for PwIDD. It had come to our notice that all over the country, there was an unregulated proliferation of clinics that reportedly provided a cure for autism through Stem Cell Therapy (SCT). The Indian Council of Medical Research (ICMR) had stated clearly that SCT was still at a very nascent stage of research as far as autism is concerned and yet many families have been spending lakhs of rupees on this unproven 'cure'. Over this past year, YCT has worked at different levels to promote informed decision-making by families on SCT. In collaboration with IIT-H, a qualitative research project was launched to study what factors govern parents' decision-making in choosing therapeutic interventions for their children. This project will be completed during the next year. In March, we conducted an online panel discussion 'Stem Cell Interventions for Autism and IDD: Research, Not Cure'. Panellists were eminent doctors from Mumbai and we provided interpreters for regional languages so that more families could attend from across the country. Preparations were made from January onwards towards filing a Public Interest Litigation in the Supreme Court asking the government to implement the ICMR guidelines and not allow the indiscriminate proliferation of clinics that touted SCT as a cure for autism. The process has been facilitated by I-Probono and senior counsels have agreed to represent us pro bono in the SC when the case comes up for hearing. The road is long, but we are committed to seeing the PIL through to its logical end.

Doctors: Stem cell therapy not a magic cure for autism

TIMES NEWS NETWORK

Mumbai: On the occasion of the International Day of Persons with Disabilities on Friday, social activists and doctors have appealed to parents of children with autism to shun promises to "cure" the condition using stem cells.

Mumbai-based Adult Support Kendra (ASK), along with 400 signatories, including neurologists, pediatricians, and parents' support groups and organisations, said, "It is extremely alarming that multiple centres and clinics in India are continuing to promote stem cell 'therapy' and some lure families by making a claim that they can 'cure' autism and appear to charge exorbitant fees for this 'treatment'."

Babita Raja, of Forum for Autism, said more centres are coming up promising such "magic cure".

A retired government servant whose son underwent stem cell therapy eight years said that there was no change in his son's condition despite the injection. "We followed up with the centre for months, but they kept insisting that my son would benefit from taking another shot," he said, adding that he had spent over Rs 1.9

A NEURO-DEVELOPMENTAL CONDITION

> Autism is a neuro-developmental condition affecting social, communication skills and behaviour

Prevalence 1-2% of population

Controversy | Treatment includes counselling, occupational & speech therapy and physiotherapy, but now some doctors offer stem cells (master cells that can give rise to other cell types with specialised func-



Cost ₹2L+ per stem cell injection/infusion
tions to 'cure' autism
> Indian Council of Medical Research holds stem cell therapy as unethical

lakh at the clinic. "If we had seen some change in our son's condition, we would have willingly taken the second shot." Other parents he spoke to also said that they too hadn't noticed any change in their children after stem cell treatment.

Developmental pediatrician Dr Leena Deshpande from Navi Mumbai said, "I have patients whose parents have tried stem cells with no effect. It is sold as a miracle cure and parents willingly spend Rs 3-4 lakh in the process. They are told their child is maintaining better eye contact due to stem cell therapy, but this can happen with regular treatment as well." While some studies ha-

ve been published in medical journals about stem cell therapy for autism, Dr Deshpande said they were not done scientifically. "In a scientific study, you have to create two arms in which only one is given stem cells, but this wasn't done in any of the published studies."

The signatories include Action for Autism-Delhi, Forum for Autism-Mumbai, National Platform for the Rights of the Disabled, as well as 117 doctors, including paediatric neurologists Dr Vrajesh Udani and Dr Anahita Udwadia-Hegde, Dr K John Vijay Sagar from NIMHANS-Bangalore and developmental pediatrician Dr Vibha Krishnamurthy.



Stem Cell Therapy is the latest in a long line of attempted cures touted for Autism and other IDDs, including Cerebral Palsy and Down's Syndrome. Opting for Stem Cell Therapy is a tough decision to make as it involves huge expenses and is an invasive and risky procedure that could result in serious side effects. Therefore, it is imperative that parents make an informed decision based on the current research and evidence.

Stem Cell Therapy for Autism and IDD: Research, Not Cure

March 5th, Saturday
6:00 PM - 8:00 PM
Free Webinar on Zoom*

Adult Support Kendra has arranged a panel discussion with senior experts in the field of Pediatric Neurology and Neural Stem Cells to help families understand the science behind stem cells and the effectiveness of stem cell therapy for children with Autism and other IDDs.



Dr. Vrajesh Udani



Dr. Uma Ladiwala



Dr. Anahita Hegde

HIGHLIGHTS OF OUR YEAR

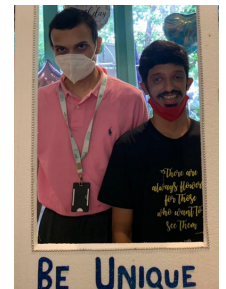
This year, we were fortunate to become a grantee partner with EMpower - The Emerging Markets Foundation. Through the grant period, we were able to focus on three concurrent initiatives. We were able to continue with our skill development for youth with disabilities; we also completed two pilot projects. The first of these involved training young women from low income households as life skill coaches for PwIDD. The second pilot involved training a group of eight PwIDD to be self-advocates and present their lives to youth groups in schools and colleges with the idea of creating awareness and sensitising the student body. This pilot saw an overwhelming success as evidenced by the very positive feedback we received. We hope to continue reaching out and sensitising more youth during the next year too.



In July this year, with the generous support from the Jankidevi Bajaj Gram Vikas Sanstha (JBGVS) we were able to acquire a brand new red auto rickshaw to keep up with the high demand for our tiffin service! This one even came with doors!



In August, we celebrated Café Arpan's third birthday with a small intimate party for just our team members. As unique as a unicorn, Café Arpan continues to grow each day and we are motivated to keep going for many more years to come.



Super proud moment for us was when we were notified by our friends at SOHO House Mumbai that our own Saurabh Kambli - who had been interning at SOHO for a year - was now being officially hired as a full time employee. Saurabh loves working there and has many friends who support and empower him every single day.



HIGHLIGHTS OF OUR YEAR

Café Arpan got a face-lift in the month of October! We wanted to focus on creating a model kitchen that could be replicated as the most suitable configuration for all PwIDD to work in comfortably.

Participating in and performing at the Bandra Steps Festival in March 2022 was an absolute delight. Thank you to our friend Tejas Menon for joining us for the performances and Thank you to the whole Steps team for inviting and including us!



SPOTLIGHT ON ABILITY

Here are a few success stories to brighten your day

Pratik Bhonsale

Pratik is a polite, well-spoken young man with a passion for travel and hospitality. Pratik first contacted us during the previous year, seeking a position with YCT - at that time we were at capacity and had to turn him away. He later became associated with us for the EMpower self-advocacy project. As YCT slowly grew, we realised that we might have a position in the organisation for his unique skill set. At this time, Pratik is in a responsible position with our tiffin service. He mans the phone, takes and lists down orders, prints receipts and delivers the tiffins to customers. He is very responsible about his work. Pratik is also under training at Café Arpan to be a counter assistant. Pratik is bright, opinionated and very curious - which makes him eager to keep learning and growing as an individual. We are glad to have him as a valuable member of our team.



Emmanuel Alleluya

Emmanuel has the biggest and widest smile at YCT. Amongst our youngest team members, Emmanuel is an effusive young man, with a heartwarming personality. His hearing impairment does not limit his ability to crack jokes and laugh with his friends and colleagues. He is a quick and eager learner and this was very evident when he breezed through his curriculum at the Skill Development Centre (SDC), quickly mastering the skills required to go on into an internship. Emmanuel is now in the middle of his internship at Arpan Food Services where he thoroughly enjoys chatting with his peers at the end of his shift. He continues to need support for adequate work completion, but he more than makes up for his lack of speed with his warm nature.





HIGHLIGHTING OUR SUPPORT STAFF

Ketkee Borkar

Ketkee Borkar, a food & beverage (F&B) professional, joined the team in December 2021. With her shy, somewhat reticent smile, we weren't quite sure what to make of her, except for the fact that she was skilled in the F&B sector. After the first week of being quiet and observant, Ketkee (or KB as we all fondly call her) has really come out of her shell and embraced not just the role - which is new for her - but more importantly, the team. The team in turn took to her very quickly as her personality is amicable and kind. She intuitively displays compassion and a deep understanding of the strengths and support needs of our team. Having Ketkee take over the reins of our food services has been fantastic thanks to her enormous culinary creativity. She constantly creates and experiments, seeks feedback and is very open to inputs and suggestions from whoever has the good fortune to be her guinea pig when she tries something new. In a short amount of time, her new additions to our menus have certainly enhanced our offerings. Besides this, KB is an invaluable team player. She totally understands the larger vision and mission of YCT and embraces it wholeheartedly.



Suhasini Sundaresan

Suhasini joined YCT as a junior counsellor in February 2021. Suha (as she likes to be called) is very bubbly, enthusiastic and the perfect candidate for our resident counsellor position. Besides working with individuals and their families, Suha also conducts group sessions for not only our neuro-diverse team, but also those outside of YCT. The group sessions are well attended and have helped participants form strong bonds with one another. A gentle soul herself, she is very good with communicating with the team members. She always goes one step further to help everyone out. With her warm and friendly personality, Suha is always ready to help out wherever needed even if the task is beyond that of her role as a counsellor.



HIGHLIGHTING OUR SUPPORT STAFF

Aishwarya Dabre & Brinal Mathias

In September 2021, Aishwarya and Brinal joined us as trainees to become Life Skill Coaches as a part of our EMpower pilot project. Both travel long distances to get to our location, but that has not deterred them from being regular and responsible. Brinal came to the pilot project with no experience whatsoever of developmental disabilities, but with an innate commitment towards inclusive practices and therefore to the larger vision of YCT. Her thirst for learning and acquiring skills was evident from the get-go. Aishwarya has completed her Diploma from Dilkhush Teachers' Training Centre and has had some experiences in working with PwIDD. She is hard-working and asks pertinent questions, seeking out help when needed. Under the able guidance of Shamane Rebello, both girls were provided with theory and practical lessons on best practices when working with PwIDD and we hope that this training will help them in their professional journey.



Aishwarya



Brinal



Jyoti Patel

Jyoti, a trained special educator, joined our training team at the SDC at the end of 2020. Jyoti has a warm, effusive personality and a keen sense of commitment to making our communities more diverse and inclusive. Her appointment at the SDC was her first job out of her training programme at Dilkhush TTC and as she says, an eye-opener as to how the adult world of persons with disabilities is so very different from that of the child. Jyoti is easily able to relate to the trainees she has in her charge as well as easily identify their strengths and support needs. She recognises that building relationships with the trainees and the entire team of YCT is important to see success in even the smallest endeavour. We, at YCT, truly look forward to seeing Jyoti grow into a leader in her chosen professional career path.

OUR FINANCIAL REPORT

PARTICULARS	FY 2021-22 (INR)	FY 2020-21 (INR)
Income		
Donation	1,50,32,560.42	73,35,906
Interest Income	14,40,193.01	11,38,901
Total Income	1,64,72,753.43	84,74,807
Expense	1,08,76,648.35	56,63,129
Opening balance carried forward	1,44,31,470.81	1,16,19,793
Closing balance carried forward	2,02,51,370.96	1,44,31,471



IN GRATITUDE

We cannot do everything we do without community support - by way of donations as well as time and energy spent helping us to better what we do. Our heartfelt thanks to the following:

- **Anand Mahajan**
- **Saint-Gobain India Foundation**
- **Sahachari Foundation**
- **EMpower - The Emerging Markets Foundation**
- **ION Foundation**
- **IP Integrated Services Pvt. Ltd.**
- **Kotak Family Foundation**
- **Rossari Biotech Limited**
- **Nandini Meir**

To our volunteers and families, a big thank you! Our team grows in numbers because of you. And they continue to make a difference in all the lives that they touch every single day.

If you wish to contribute towards our cause, you can do so using one of the methods below:

By Cheque -

Made out to '**Yash Charitable Trust**'.

By Direct Bank Deposit -

For Indian Donors

Account Holder: Yash Charitable Trust

Bank and Branch: Kotak Mahindra Bank, JVPD

Savings Account No.: 7711476797

IFSC Code: KKBK0000661

Scanning the code below will take you directly to our donation page -



All eligible donors may avail of tax benefits under Section 80G of the Income Tax Act, 1961

For International Donors

Account Holder: Yash Charitable Trust

Bank & Branch: SBI, New Delhi Main Branch

FCRA Current Account No: 40195423413

IFSC Code: SBIN0000691

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