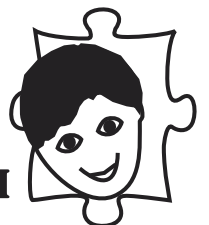


autism network

VOLUME 16, 2021



ACTION FOR AUTISM



autism network

2021

VOLUME 16

Action For Autism is a registered, non-profit, national parent organization. Autism Network is published by Action For Autism to provide information on education, therapy, care and to provide interaction for families and professionals across the country.

Autism Network is a forum for expressing diverse opinions. Action For Autism does not hold itself responsible for opinions expressed by individual writers. Publication of any information does not mean support of Action for Autism.

Autism Network does not accept advertisements. Expenses are met through memberships, donations and sponsorships, from our readers, friends and well wishers. The journal is for free distribution.

INFORMATION

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YOUR CONTRIBUTIONS

Do you have any comments, suggestions to offer? Information and experience to share? We look forward to our readers' participation. Send letters, articles, illustrations to: The Editor, Autism Network at the above given address or E-mail: actionforautism@gmail.com

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In referring to the child with autism, Autism Network often uses 'he', 'him' and 'his', not as a prejudice against the girl child with autism, but for reasons of simplicity and because the vast majority of children with autism are male. However, many articles also use 'she', 'her', and 'hers'.

Cover Illustration

REFLECTIONS by KABIR VERNAL, 10 years old
Kabir is primarily non-verbal. He is homeschooled, loves playing with sticky textures, paints and creates art.

WISHLIST !

- Computers and computer accessories: keyboard speakers, mouse
- Computer games, X Box Konect
- Music systems: CD/MP3 players, head phones, bluetooth speakers
- Washing machine, mixer grinder, induction plate, electric kettle, table mats, door curtains, waterproof aprons
- Trampoline, bean bags, indoor plastic slide, see saw, handyman kit: hammers, pliers, screw drivers, small drilling machine, nails
- Playdoh, pull along toys, light & sound making toys, Lego, pretend play toys: dolls, doll house, doctor's sets, furniture sets, grooming sets, kitchen /tea sets
- Classroom stationery: markers, A-4 sheets, A-3 sheets, acrylic paints (250 ml bottles), enamel paints, primers, paint brushes, old newspapers, glossy magazines
- Plastic baskets/ jars & containers with lids
- Volunteers: For yoga, art & craft

If you want to help, write to AFA or call:
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PAGE ONE

The year started uncertain. We began opening up gingerly getting back to careful though distanced physical work. And as we began considering the possibility of things getting back to pre-pandemic ways, bam! We were hit by another and far more devastating wave of the virus. As the country reeled from the mayhem of the virus, we did our best to continue our work without break. Our services remained online, with many hiccoughs along the way as AFA team members dealt with covid infection themselves or for their family members. A challenging few months later, as the year comes to an end, we are hopefully moving out from the dark shadow of this terrible virus.

Our 2021 issue of Autism Network offers some great reading, with pieces by both autistic and neurodivergent writers. There have been a few studies on a possible higher occurrence of obesity in the autistic population as compared to neurotypical population, but no likely reasons have been found.

Devrupa Rakshit, writing from her lived experience suggests that: "...sensitivity to certain food textures can make autistic individuals eliminate many fruits and vegetables from our diet – forcing us to rely on processed food. To add to that, some of us also tend to use food – especially the processed kind – to cope with the stress that comes with living as a neurodivergent individual in a neurotypical-dominated world. And for quite a few of us,

eating food – especially the 'crunchy' variety – can also be a stim. Poor impulse control, that many autistic individuals experience – doesn't make cutting down on food any easier either. And to make matters worse, some of us also struggle with physical activities."

The article is an absolute eye-opener and once again highlights the importance of viewing autism and for that matter any other form of diversity from the perspective of the divergent individual, rather than a majoritarian lens.

Most parent accounts of living hands-on with an autistic offspring tend to be from mothers. We are delighted to feature a piece by the gentle and inimitable Anand Kumtha – father, professor, math geek, game designer and advocate for autistic people – that more than anything else brings out the easy camaraderie that springs from a shared love of music, and unconditional love. Anand and his son Kabir's equation and exchanges truly demonstrates the fun, that has to be at the fundamental of living a joyous life.

In the coming year as the organization gets back to our pre-pandemic ways of working, we hope that the Autism Network will be able to spring back to our old publication schedule that has been so challenged by the restrictions brought about by the pandemic.

Wishing all our readers a safe, happy, virus-free, and healthy times ahead.

Reference:

Research adds heft to link between autism and obesity – By Nicholette Zeliadt
<https://www.spectrumnews.org/news/research-adds-heft-link-autism-obesity/>

How Autism Impacts My Relationship with Food

Devrupa Rakshit*

I am a 29-year-old autistic woman. I realized only last year why I've been so averse to most fruits all my life.

Before I take you through my realization, here's my background. I self-diagnosed myself as an adult a couple of years back, and received my formal diagnosis earlier this year. As you can see, I have spent a major chunk of my life not knowing about my autism. Naturally, like most other late-diagnosed (or, even undiagnosed) autistic individuals, I thought I was just 'weird'. My strong dislike of fruits was chalked up as one of my 'weird' traits by my family, and my limited circle of friends. They said I'm just an 'irresponsible', 'picky', 'unhealthy' eater. Over time, I internalized their take.

It wasn't until last year – when I was trying to understand how my neurodivergence guides everything from my choices of career, of food, of clothing, of partner, of... what have you – that I decided to investigate my feelings about fruits.

At this point, I had begun to understand how certain textures can make me extremely uncomfortable. It's an understatement, of course, but I'm not sure I have the right word to describe the level of discomfort certain textures can make me feel – it's like a debilitating kind of disgust; pretty much the way I feel about lizards. In addition, like most autistic people I've interacted with, unpredictability can be a meltdown-inducing source of stress for me.

Fruits, interestingly, trigger both my sensitivity to textures and my fear of unpredictability. How can I ever predict that the next apple I eat will taste exactly like the previous one? Leave alone 'exact', at times, they're not even remotely the same. To top that, the texture of each individual fruit can vary across the same species. I mean, it's only natural – and, well, nature is unpredictable.

In *arguendo*, even if the textures of the same species of fruits were identical, the textures of most fruits can still make me extremely uncomfortable. Mangoes, for instance, are a collective favorite of the Indian population, right? Well, I don't like them. They're too soft and gooey for me. But will I gulp down a tetra pack of processed mango juice? Yes, happily. So, you see, my problem lies in the texture of fruits, and their lack of consistency – not necessarily in the way they taste or smell. Although with ripe jackfruits, even taste and smell are a problem – in addition to the texture of its skin, of course. Would you believe me if I told you I'm mortally afraid of jackfruits?

As Emily Kuschner, a psychologist at The Children's Hospital of Philadelphia had written (*albeit* for an organization I absolutely despise¹): "Research also tells us that many individuals with autism tend to have strong preferences for carbohydrates and processed foods while rejecting fruits and vegetables. This, too, may reflect an aversion to strong

¹Emily Willingham, 'Why Autism Speaks Doesn't Speak For Me' (*Forbes*, 13 November 2013) <<https://www.forbes.com/sites/emilywillingham/2013/11/13/why-autism-speaks-doesnt-speak-for-me/?sh=388b5be31527>> accessed 8 December 2021

tastes and textures."² Turns out, I was right, and more hearteningly, I am not alone.

Actually, my aversion towards certain foods does extend to vegetables too, just like Kushner stated. However, unlike most fruits, vegetables are often cooked. And, to a certain extent, that takes care of the 'unpredictability problem'. Some textures can still be overpowering though. *Parwal*, which lies at the extreme worst end of that spectrum, would still make me retch instantaneously. A *lauki* may, or may not make me retch – it's a gamble, but one that I avoid. However, I can still have a *karela* even if it's more or less bitter, more or less soft than the previous *karela* as long as they are cooked in the same way. So, you see, with every fruit and vegetable, it's a combination of texture and consistency that determines whether it'll be able to eat it happily, whether I'll hate the universe and my own existence if I'm forced to ingest it, or whether my body will simply throw (up) the food out.

Processed food, of course, is a joy to me. It doesn't generally contain overwhelming flavors that I'm not prepared for, and it's uniform and consistent – both in terms of texture and taste.

However, as Kushner had explained, relying excessively on processed food to meet one's dietary needs, while excluding fruits and vegetables, can "unfortunately... lead to nutritional deficiencies and excessive weight gain, especially if exercise is limited."

The latter part, about limited exercise, is actually something I find a tad terrifying in the context of my dietary choices. "Children and

adults with autism are at risk for an inactive lifestyle and obesity," an article I read online said. I know autism is a spectrum and I'm sure there must be autistic individuals, who are into sports, exercising, going on physical adventures, and so on. But I'm not one of them. Neither are most of the autistic people I know personally. Is it because of our poor coordination? Is it perhaps about the low muscle tone that many autistic individuals live with? I don't know. But it worries me to think of how our limited dietary choices can affect our health – both mental and physical – in the long run.

And you know why I'm even more concerned? Because some of us use food as a coping mechanism to deal with the stress of navigating a neurotypical world. Food, and the comfort it can bring to many of us, helps us tackle the discomfort life can throw at us regularly. The more often the latter happens (which, let's accept it, is like a hundred times every day), the more we rely on food to derive comfort.

"I... used food as a way to escape, which is the coping mechanism that caused me to develop issues with my weight over the years... Right after social interactions, I tend to eat a lot, and I eat wrong because I need to comfort myself," an autistic individual I once interviewed for work had told me. In fact, it was her issues with weight that led her to a counselor, and subsequently, to her autism diagnosis. "I found out that I had been doing this since childhood, and that's why I've kind of been overweight my whole life," she said. She ended up getting a surgery to reduce the size of her stomach in a bid to cut down on her food intake.

²Emily Kushner, 'What Is It about Autism and Food?' (*Autism Speaks*, 5 September 2018) <<https://www.autismspeaks.org/expert-opinion/what-it-about-autism-and-food-0>> accessed 8 December 2021

Like her, I too rely on food – like French fries, momos, biryani, and butter chicken; nothing 'healthy' – to get through difficult days. Or, maybe, I should just replace 'difficult' with 'most' because, truth be told, most days are difficult. So, for me, a person who grew up almost obsessed with every aspect of her appearance, my dysfunctional relationship with food has ensured I'm often teetering on the verge of an eating disorder. And yet, I fail dismally at replacing processed, not-great-for-health foods with primarily plant-based, relatively-more-healthy ones.

A study from 2019³, which was investigating the link between processed foods and obesity, made an interesting discovery. "There may be something about the textural or sensory properties of [processed] food that [makes people] eat more quickly... If you're eating very quickly, perhaps you're not giving your gastrointestinal tract enough time to signal to your brain that you're full. When this happens, you might easily overeat," Kevin Hall from the National Institute of Diabetes and Digestive and Kidney Diseases in Bethesda, who led the research, explained⁴.

So, basically, our sensitivity to certain food textures can make us eliminate many fruits and vegetables from our diet – forcing us to rely on processed food. To add to that, some of us also tend to use food – especially the processed kind – to cope with the stress that comes with living

as a neurodivergent individual in a neurotypical-dominated world. And for quite a few of us, eating food – especially the 'crunchy' kind⁵ – can also be a stim. Poor impulse control⁶, that many autistic individuals experience – doesn't make cutting down on food any easier either. And to make matters worse, some of us also struggle with physical activities. It's like the odds are stacked against us, right?

Again, given that autism is a spectrum, this is probably just a small subset of people. But it happens to include me, as well as people I know. So, naturally, I'm concerned. Perhaps, if research by heavily-funded organizations focused on addressing very real, very relevant concerns like this through research – instead of trying to 'cure' autism – we'd know how to allay my fears better. Until then, well, I can stare into space as I worry about my health while battling to urge to munch my way through a bag of potato chips.

**Devrupa Rakshit is a queer, autistic feminist hailing from Jamshedpur. She started her career as a lawyer in Mumbai after graduating from one of the country's top national law schools, but has been working full-time as a journalist for two years now. She also holds a degree in painting, and as a bilingual poet and storyteller, she was one of the top three finalists at Signature Masterclass in 2020. For the past couple of years, she has been working on her first book, which explores how lived experiences of different sexual assault survivors often diverge almost completely from the 'victim'-stereotype.*

³Kevin Hall, Alexis Ayuketah, and Ors., 'Ultra-Processed Diets Cause Excess Calorie Intake and Weight Gain: An Inpatient Randomized Controlled Trial of Ad Libitum Food Intake' [2019] 30(1) Cell Metabolism <<https://doi.org/10.1016/j.cmet.2019.05.008>> accessed 8 December 2021

⁴Yella Hewings-Martin, 'Processed foods lead to weight gain, but it's about more than calories' (*Medical News Today*, 17 May 2019) <<https://www.medicalnewstoday.com/articles/325194>> accessed 8 December 2021

⁵'Is eating a stim?' (Reddit, 19 July 2019) <https://www.reddit.com/r/autism/comments/cexglf/is_eating_a_stim/> accessed 8 December 2021

⁶'The Relationship Between Autism And Impulse Control' (*Carmen B Pingree Autism Center of Learning*) <<https://carmenbpingree.com/blog/the-relationship-between-autism-and-impulse-control/>> accessed 8 December 2021

Stem Cells for Autism

Dr. Uma Ladiwala*

When he was 3 years old, Anu and Virat's son Aarav was diagnosed to have autism. After the initial shock, they set about trying various kinds of rehabilitative therapies and several alternate ones too. Although there was some improvement, they were impatient to find a cure, and so when Anu came across an advertisement for stem cell therapy for autism in the parents' chat group they wondered whether this was worth trying. Naturally, there were many questions in their minds, and they needed further clarity before they could make a decision. What are stem cells? Would the stem cells really cure Aarav's autism? Are there any side effects or other risks involved?

What is Autism?

Autism Spectrum Disorder (ASD) or autism, is the term for a group of conditions which have similar behavioural symptoms that appear early in childhood. These behaviours can be broadly grouped into those due to communication deficits and repetitive sensory-motor behaviours. Symptoms vary in severity, and affected individuals can be placed on a spectrum depending upon the extent of support they need. The condition is not uncommon and it is a fact that it is more prevalent now than in the past two decades [1]. Scientific research has provided many insights into it (although it is not completely understood), and the outlook for affected individuals is much more optimistic than it was 50 years ago [1]. Many are able to live productively in their communities, and some show significant improvement by adulthood. A subset of individuals, however, are unable to live independently and require support, putting their families under social and financial pressure.

The precise cause for autism is not yet known. Several contributory risk factors - both genetic and environmental - have been identified. There is, so

far, no cure for it, and a few symptomatic treatments are the only recourse that parents have [2]. In such a scenario, numerous alternative therapies have been tried with little success. In recent years, stem cell "therapy", although still experimental, is being increasingly offered as a treatment for autism.

What are Stem Cells?

Human bodies are made up of trillions of cells of different types and functions. Stem cells are the "parent" cells found in almost every organ of the body which can give rise to other cell types with specialized functions, such as liver cells, blood cells, brain cells, etc. In the early developing embryo, stem cells (called embryonic stem cells) can form almost all specialized cell types found in the body, but stem cells in adults have a much more limited capacity to form specialized cells. As a rule, adult stem cells can only give rise to cell types of the organ they are found in. For example, stem cells in the brain can only form the different types of brain cells. The bone marrow has two main types of stem cells- one which forms bone, cartilage and fat and the other forms blood cells.

Since stem cells can form new specialized cells, stem cell therapies aim at regenerating or replacing cells that are affected by disorders and diseases. This can be done by removing stem cells from the patient or a donor and making them into the desired specialized cells in a laboratory (by adding reagents known as growth factors) before transplanting them back into the patient. Another method is to take out stem cells from a patient's body, remove and discard other unwanted cells and inject the remaining stem cells back into the patient, in the hope that they will migrate toward the damaged organ. This could happen because in the damaged tissue are found certain molecules that can attract the stem cells. Not only that, once they reach the damaged site, various

molecules like growth factors can transform the stem cells to the specialized types of cells required to replace the lost cells. This has been observed in studies on animals like rats [10].

Causative Factors for Autism

To re-iterate, the precise cause for autism is still not known. Several contributory risk factors have been identified including both genetic and environmental factors and the interaction of these. Genetic studies of autism have identified mutations (variations) that interfere with typical brain development of the fetus during pregnancy and through childhood. These genetic mutations affect the connections and networks that are formed between cells in some specific areas of the developing brain, particularly those regions involved in social-emotional processing [2]. Besides this, there are some other differences between autism and neuro-typical brains, including disturbed layering of cells in the grey matter of the large cerebral hemispheres and reduced blood supply in some regions [3]. Not only are the changes in autism restricted to the brain, but there is also evidence of immune system disturbance (seen in some groups of autistic individuals, not all), intestinal disturbance, effects of exposure to toxins such as heavy metals, and hormonal imbalances. Thus, multiple systems appear to be involved in autism, making it difficult to find one treatment that works for all.

In a nutshell, autism is a complex condition and leaves many questions unanswered. So, claiming a treatment for such a condition where the cause is still largely unclear, should be done with extreme caution.

Stem Cell Therapy

Stem cell research has made rapid progress since its beginnings about 50 years ago, and currently stem cell therapy is approved and used only to treat some cancers and other disorders of the blood and immune cells [4-7] by transplanting bone marrow stem cells that form blood and immune cells to replace the diseased cells.

Clinical Trials of Stem Cell "Therapy" for Autism

Stem cell "therapy" has not been approved for autism. A few clinical trials of stem cells for autism have, however, been carried out and published (reviewed by Price in [8]). The trials are based on a very weak scientific rationale according to Price [8], because of certain properties of stem cells. Stem cells naturally secrete some proteins that suppress harmful immune responses (inflammation) and others that are growth factors for cells around them [9]. A few also help the growth of new blood vessels and reduce death of surrounding cells [9]. So, why is the rationale weak? Firstly, it is not clear whether immune disturbances in autism have any connection to the symptoms and thus even if the stem cells had some effect on the inflammation, would it alter the behavioural symptoms or the underlying brain changes? Secondly, the immune changes are not found in all individuals with autism and there was no attempt by the clinical trials (except one) to assess immune parameters in subjects either before or after the stem cell infusion so the effect is a presumed one, if it exists at all. Thirdly, do the injected stem cells reach the brain at all, if so how many and how long would they survive? There is some evidence for this from stem cell research in rat models of autism, although it has been well established that what works in rodents does not usually work similarly for humans [10]. Even if they did reach the brain, how would a shot of stem cells alter the genetic and environment-influenced structural brain networks that have formed over several years? What about the other systemic changes seen in autism such as gut and hormonal disturbances? None of the published clinical trials have assessed these.

Various types of stem cells have been used, including umbilical cord blood stem cells and bone marrow stem cells. These have been sourced from donors or from individuals themselves. The route of administration of the stem cells is either by intravenous injection or injection into the spinal region.

In a review of clinical trials of stem cell "therapy" for autism [8], as of December 2019, there were 13 clinical trials of stem cell therapies registered on clinicaltrials.gov (the official National Institutes of Health, USA, clinical trials registry). Of these, seven were completed. Of the completed and published trials, only one was a well-designed, controlled clinical trial. A controlled clinical trial is one which includes a group of similar subjects for comparison, who are either treated with a placebo (a substance that is inert or has no therapeutic effect) or not treated at all. This one trial showed no significant benefit of stem cell therapy for autism in that there was no significant change in any tests post-treatment over pre-treatment assessments. Only 1 of the clinical trials looked at changes in immune markers in the subjects. Many of the trials established modest evidence of safety, although there were some untoward side effects such as epileptic seizures, headache, nausea and vomiting when the stem cells were administered into the spinal cord covering. Most studies had short follow-ups, varying from 6 months to 21 months. Overall, there was very little hard (scientific) evidence of stem cell "therapy's" actual effectiveness for treating autism. In fact, experts in the field have questioned the legitimacy of these trials with regards to their scientific basis, the trial design, methods of measuring the results, and their interpretation. The variability in the studies makes comparisons difficult, thus making it harder to arrive at any robust conclusions [8]. Further research is warranted before any firm conclusion about stem cell treatment in autism can be arrived at.

Lack of Regulation of Stem Cell "Therapy"

It is regrettable that the potential of stem cells has spawned a rampant stem cell industry for conditions for which no effective treatment or cure exists- such as autism - in many developed and developing countries worldwide [11], including India. Most of these take advantage of a loophole in regulations that may exist, which enables stem cells extracted from the individual's own body to escape stringent regulations that are applicable to other types of stem

cells. Thus, despite insufficient evidence of their effectiveness, stem cell 'therapies' are carried out in unlicensed clinics, sometimes under the guise of "clinical trials" and usually with exorbitant charges. In India this has given rise to a "stem cell tourism" with websites advertising cheaper stem cell therapies than in the West. One such website listed a choice of 118 centres conducting stem cell therapy for autism and other conditions, in different cities and towns of India. These are replete with exaggerated testimonials and unsubstantiated claims of "cures" and "return to normalcy" after stem cell "therapy". Anecdotal reports on social media and in newspapers further compound this impression.

Recognizing this state of affairs, the Indian Council for Medical Research (ICMR), which is the apex regulatory body for bio-medical research in India has formulated guidelines for stem cell therapy for human diseases [12]. Herein they categorically specify that **"Critical review of the studies reported so far does not support the use of stem cell therapy over and above the behavioural and supportive therapies for ASD. Recommendations (2021): Based on the review of available scientific evidence, stem cell therapy should NOT be offered as a standard or routine therapy to patients with Autism".** Further, **"Participants in a clinical trial should not be made to pay for any expenses incurred beyond routine clinical care and which are research related including tests, investigations and any interventions (such as stem cells). This is applicable to all participants, including those in comparator/control groups. Participants in a clinical trial should be provided compensation in the event of any harm or permanent injury or death due to the use of experimental stem cell therapy."**

The ICMR has also objected to amendments proposed by the Ministry of Health and Family Welfare to the Drugs and Cosmetics Rules, 1945 on the regulation of stem cell procedures. The amendments seek to exclude minimally manipulated stem cells (stem cells that have not

undergone much processing after being removed from the body and before being transplanted again) from being defined as new drugs. Such an exclusion will mean that these cells will not need to be tested in clinical trials for efficacy and safety before they receive market approval. If passed, these amendments may legitimise the use of unproven stem cell therapies in India [13].

In conclusion, the current use of stem cells as "therapy" for autism is as of yet unverified and not recommended [12]. Further research is required to determine its safety and efficacy. Parents of individuals participating in clinical trials for the same need to be aware of the financial and ethical guidelines as formulated by the ICMR (see above). The current mainstays for managing autism are still the standard behavioural and supportive therapies. Beyond these, the question that still needs to be considered is whether autism needs to be "cured" at all or can it be considered another aspect of human diversity that needs more inclusiveness?

**Dr. Uma Ladiwala qualified with an M.D. in Pathology from the Grant Medical College, Mumbai. Some years after, she switched to a career in basic scientific research, dedicated to basic neuro-immunology research, with post-doctoral stints in Mumbai and abroad at institutes in Sweden and Canada. On her return to India in 2001, she worked at the Tata Institute of Fundamental Research (TIFR), Mumbai, researching on neural stem cells, and continued this further when she set up her own lab as Faculty at the new UM-DAE Centre of Excellence in Basic Sciences, Mumbai. She has authored and published several articles in recognised Indian and international journals and presented at a number of national and international conferences.*

She has taught students at the undergraduate, Master's and PhD levels. She has also worked at training school science teachers for several years. She has recently joined Adult Support Kendra, Yash Charitable Trust as Research Consultant.

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Men at Home – *Ek Filmi Nautanki*

Anand Kumtha*

1. Mard Ko Bhi Rona Aata Hai...

Though a man of few words, the young man had a way of expressing himself through Hindi songs (sometimes through English or Marathi songs too). Right from childhood, he had a preference for this mode of expression through songs. His family, especially his dad, would also at times converse with him through songs, just for fun.

The young man's mom had to be out of town on Government assigned work for over three weeks. On the day before she left, while the mom was packing away, he started singing "*Pardesi pardesi jana nahi; mujhe chod ke, mujhe chod ke...*" She promised him to come back on the date she had marked for him on the calendar with her entire schedule.

And she left for her long outstation assignment.

The dad and he were both working from home and working at home too, as they had stopped all their regular house-help during the pandemic. Since the dad was also working, the son's schedule had a lot of free time and he indulged in quite a few activities that he loved to do – music being the top favourite.

A week passed happily. Every day at around 5 p.m., after work, the mom would make a video call to talk to them. But of course, all three were missing each other a lot. This was the first time after his grandfather's death that his mom had gone out of station for such a long time. So, the house felt emptier.

The dad was using this time to also go through, clean up his stuff in the house and do away with old unused stuff. While clearing his shelf, the dad found the son's school report from when he was in his

teens. Remembering the son's turbulent teens in the terrible school, the dad remembered how the son would assert himself if he felt he was not respected by the authorities (Once a teacher had even reported that he sang "*We don't need no education*" in the class).

The dad thought: Yes, my sweet boy in those days had that spark of rebellion in him – just like me! (this of course he said to himself unashamedly)... I wonder why, post his teens he has become so very, very over-understanding of others? Where did we go wrong as parents? Why has he been the most mature and adjusting person in the house during this Corona year even when we, his parents have not always been in a great shape?

One day the dad heard some news about his very close family friend that truly saddened him. He kept a straight face throughout the day, but at night, when alone in his bed, he sobbed. Just let the tears flow... so that the next morning he could be fine for the son...

Next day, the dad went around with a straight face thinking that the son would not notice that he was disturbed.

That very day, due to longer work hours, the mom could make her video call not at 5 p.m., but at 7 p.m.

And that very day onwards, the young man started singing loudly. One after the other, all the "*Pardesi*" and "*Tadap tadap ke*" type of songs came out from his repertoire – some that the dad did not even know. Dad thought: *Nautanki sala! Ab bas bhi kar beta!*

At times, the dad held him close, at other times asked him what was the matter, sometimes talked to him about mummy coming back on the designated day;

he also cooked his favourite food ... The dad even confessed to the son how much he himself was missing the mom. The son looked at him like:
Chalo, aur ek nautanki...

Despite all efforts, the loud singing - squealing would stop only for some time. The dad was happy that the son had stopped being the over-understanding person and that he was expressing his feelings rather than bottling them up. He acknowledged that it was the son's wish to sing the way he wanted to in his free time and never asked him to stop singing and went about doing his things and getting the son to do his routine things, generally talking to him in the most natural matter-of-fact way. If the dad asked or gesticulated to the son to lower the volume of singing, then the son would oblige; but the dad would use this instruction sparingly. The young man was almost relentless, except the sleeping hours that became totally erratic. But even if he got up at unearthly hours, the son would sing in his own room or the drawing room but did not usually try to wake up the dad (although the dad would invariably wake up with the slightest sound).

On a Sunday morning, they woke up together and met in the drawing room. The first thing they usually did was to brush their teeth. With that red gel toothpaste that is supposed to give you all-day freshness and confidence.

As he finished brushing his teeth, the young man burst out crying. Helplessly. He must have cried just about 4 - 5 times in all of his adulthood. The dad held him close. Cry your heart out, my son, he said in his mind. They both sat down on the bed. The dad offered him his lap. The son took up the offer and rested his head on the dad's lap for just 10 seconds and then again sat up in an adult fashion. They both just sat together for some time, arms on each other's shoulders. The son gathered himself.

Then the dad made some tea. Both the chai lovers enjoyed their morning tea together.

2. *Tasveer*

The loud singing continued, but now there were bigger and bigger gaps in between the bouts of loud singing. It was like - ok now I feel anxious, I sing. I block out everything else. Then I again go about my business (Didn't the dad himself sing all kinds of zany songs including "*Darr lage to gana ga*" to his son right from his childhood all through his life? The son was just following the advice).

The dad too had his own emotions (vis-à-vis his friend's sad news) under control now and was again back to his usual P.J.s and buffooning.

It was a quiet night. The dad was in his room working on his laptop with the table lamp on. The young man was quietly sitting in his own room. After some time, he crept in very quietly to his dad's room, tiptoed and sat on the bed just behind the dad and started singing to him a song that he had never ever sung before, in a very soft voice:

*"Jab tum chale jaaoge to yaad bahot aavoge
Dil behlane ki koi tadbeer dete jana
Aaj mujhe tum apni tasveer dete jana..."*

Am I hearing correct? The dad waited till he repeated the entire *mukhada*. The dad decided not to be emotional. Closing his laptop, he got up, went and slept on the bed, putting his head on his son's lap. Eye to eye, holding his hand, he directly came to the point and said warmly:

"You, mummy and papa – we all love each other. If mummy is not there, then papa is there for you. If papa is not there, then mummy is there for you. And if both mummy and papa are not there, there will be someone to care for you. You don't need to worry. There are so many people - your family and friends, who love you and care for you. And you can take care of yourself too. You do your work. You know who loves you, who cares for you. You know what you want and what you don't want. I am so proud of you! You are strong!"

The young man was giggling as the dad repeated "You are strong!" like a mantra.

Then the dad listed the names of a lot of people who cared for the son and asked him, "Should we make a big *tasveer* of all the people who care for you? I will take printouts of their photos."

That was the programme fixed for the next morning when the printer's shop would open.

The son was smiling.

Then they indulged in their favourite pastime: lying on the bed side by side singing. It was the dad who sang today. Songs like "*Jeevan ke din, chote sahi, hum bhi bade dilwale...*" and "*Suraj se aankhein mila, Taaron ko dharti pe la, Yeh dharti teri hai, Yeh sapne tere hai, Aur sab apne tere hai...*" etc...

The son heard him out patiently for some time (*aur kya karta bechara?*) until it was dinner time, when he promptly asked his old man to cook his favourite pasta (As he knew dad was pampering him by cooking his favourite foods, he had stopped asking for 'dinner' – a stupid generic term anyway – and would make a clear *farmayish* for particular food items).

After eating, they both slept soundly.

The next morning, they created the *tasveer* together, both choosing the photos of the close persons. Dad called it 'Circle of Care' with the son's photo in the center and the people who cared most for him in a circle around him. No words; just the photos. A printout was taken and put up on the son's cupboard.

The son was all smiles looking at the photos. Through the day, he would look at them intermittently.

(But it would have been too filmy if he gave up his anxiety so easily, wouldn't it?)

3. *Nautanki Jaari Hai!*

... As more days went by, there was much more calm at home, but of course both the men were still missing the woman of the house.

They started some joint work to get over this.

The young man joined his dad in tidying up dad's things (yes, not his own, mind you) and soon made sure that the dad couldn't find many of his things in their place. : He still continued to sing songs - which was his favourite pastime anyway. It was not so much the loud squealing, but more in the usual tone.

The dad joined the young man in his singing, also at times performing some of those crazy *banjaran* steps of the "*Pardesi pardesi jana nahi*" song...

There was a lot of giggling, but sadly no other audience to clap and whistle at the *nautanki*.

Slowly the son and the dad's sleep pattern and activities settled back to the usual ones. As the calendar showed the mom's return date come closer – from weeks to days – the son's songs became *ekdum sureela gayan* and the choice changed to random ones, extending anywhere from "*Dil ka bhanwar kare pukar*" to "*Dharati maa ka maan*" and from "*Saamane yeh kaun aaya*" to "*Mere haath mein, tera haath hai*"...

Sometimes when the dad would be immersed in his work, the son would sing in Marathi: "*Pustaknantarvacha; atakhelanacha*" ("Read the book later; play and dance now").

They would also have some joint jamming sessions singing with a home orchestra of all sorts of percussion and wind instruments. And they would do a whole lot of other things...

But of course, when the mom did a video call, at times suddenly, she would get a voluntary special

performance of “*Pardesi*” or a hopeful “*Mera piya ghar aaya*”.

(Bete ka itna haq to banta hai na!)

4. Mummy ki Ghar Wapsi

Finally, the calendar showed up the day of the mom's return with a smiley. There was excitement all day long. The dad had cooked some Chicken *Dhanshakh* with caramelized rice, a dish that all three of them liked. The day went by with extra excited singing.

Mom rang the bell at night after arriving at the airport and finishing off with the Covid test etc. Dad opened the door and there she was!

Now there was super excitement! But this spoilsport dad hugged his son and told him, "It's Corona times, let mummy first take a bath, then you can give her hugs and kisses. Till then you can give me a hug instead!"

Mom was taking her time in the bath, getting thoroughly sanitized. After some time, the son went and stood just outside the bathroom door and sang the song (directly starting from the third line, after skipping the first two), “*Par tum ne der lagaa di, ruk ruk ke baat badhaa di!*” He repeated the performance once more and then stood in the drawing room with an eye on the bathroom door.

When she emerged all clean and asked for a hug and kisses, he took them all smiling, but a bit passively. Then he quickly went to the sink, brushed his teeth for the night with that red gel toothpaste that gives freshness and confidence (If mummy is super clean with a head bath, then I should be at least this clean, right?). He then hurriedly went to her room and showered her cheek with some soft kisses.

The smiley on the calendar was smiling.
(And that's a no-brainer, of course).

(Disclaimer: Mein jo kuch bhi kehta hoon sach kehta hoon; sach ke sivay kuch nahi kehta – Govinda's line from the song “Stop That!”).

** Anand Kumtha is the proud father of a young-adult entrepreneur with autism.*

A professor, writer and researcher in Mathematics and Statistics, he has trained in Narrative Practices and Social Role Valorization.

As a social activist, Anand has upheld the right to equality and dignity for all marginalized sections of society, including autism families.

Among his many pursuits, he is a writer of both fiction and non-fiction and a poet. Writing, directing, producing and acting in street and stage plays; composing and singing songs for a street band and for documentaries have been some of his passions.

Over the years, Anand has used his many skills to develop games, and organize and research leisure activities for persons with special needs ('Khel Khel Mein – Play Ideas for Special Persons' – <https://www.facebook.com/PlayIdeasForSpecialPersons>).

Above all, he believes in working for a fair, just and discrimination-free world for all.

Pandemic Reflections

Dr. Shubhangi Vaidya

The COVID 19 pandemic disrupted the world as we knew it. For those of us with a family member with Autism, the crisis magnified manifold as we struggled with new routines, the absence of safe, familiar spaces and above all, the fear of the disease striking us and our families. The devastating wave that swept our country in the months of April and May 2021 will be etched forever in our memories. The escalating daily number of cases, deaths, shortages of oxygen, hospital beds and essential medicines, no longer were news stories that happened to someone else, they were realities that struck very close to home. Every day brought news of friends and colleagues getting infected. Throughout the Pandemic my son V and I had followed COVID norms and protocols to the hilt. Masking, sanitising hands frequently, maintaining physical distance, giving up many of our pleasures like shopping and eating out-we took all possible care and precautions. However, just a few days after my first Vaccination, I tested positive. As I received the news, my mind was in a whirl. What on earth were we going to do? How was I going to isolate myself and keep V safe? How were we going to manage meals, housework, medical requirements and, God forbid, any medical emergency? Who would look after me? Who would look after V? I was terrified and felt utterly helpless and alone.

After having a good cry, I composed myself and got into action mode. I broke the news to V in a very matter of fact way, and assured him that I wasn't going to die (as that was the first thing he asked!!) I moved to the spare bedroom with my belongings and marked the boundary beyond which he could not approach me with chairs. Essential phone calls were made. The doctor, the chemist, the provision stores. Family, friends, neighbours and colleagues. The siege had begun.

The worst thing about the COVID pandemic, which makes it so different from other illnesses, is the fear of contagion and therefore the difficulty of maintaining human contact. But to our relief, all our needs from food to medicine were literally delivered at our doorstep. Kind neighbours assured us that they were just a phone call away, and gave us tremendous moral and material support. But the real hero of those dreadful days was young V. He too wept bitterly, but a chat with his teacher helped him to come to terms with the situation. Cooking and serving food, washing the dishes, providing thermos flasks of hot water and tea, boiling water for steam inhalation, cleaning and tidying the house – he did it all, all by himself. He was extremely careful of hygiene and COVID protocols, and remained double-masked the entire day, which must have been an extremely uncomfortable experience for him.

Of course, living in the same house as a COVID patient, it was inevitable that he too would catch the infection, and sure enough, after five days of devoted care of his sick Mom, he developed a fever and tested positive too. With both of us COVID positive, we could dismantle all the barriers that separated us, and be together, Mom and son, again. Mercifully, my symptoms had considerably reduced by this time, and I could resume my role as care-giver to my child. Fortunately, he had a mild illness, and also recovered at home. It was only after we both completed the mandatory three weeks of home isolation that I could finally breathe a sigh of relief.

Looking back on those terrible days, I realise what a huge milestone was crossed. Our care-giving roles had been reversed for a time, and V rose to the occasion magnificently. In the most trying and difficult of circumstances he had competently and efficiently done what was required of him, and

above all, regulated his own feelings, anxieties and fears and displayed great equanimity. Throughout those dark days, he continued to attend his online sessions with Aadhar Vocational Centre at Action for Autism, and this gave structure to his days and things to look forward to. The companionship and support he received helped him to cope and overcome.

During this period, I had also received sad and shocking news of the deaths of some very dear friends and family members due to COVID. The stream of bad news on TV and the disturbing images and non-stop bombardment of information

was also extremely detrimental to one's mental health. Although I had recovered physically, my heart and soul were scarred and shattered and I had completely lost my confidence and poise. In this situation V was my greatest source of inspiration and support. His happy spirit, his enjoyment of the little pleasures of life, his laughter, spinning and singing, renewed my own joie de vivre. I realised how lucky we were to have seen the crisis through; how blessed we were in our friends, family and the autism community. 'We shall overcome' is a song that V learned as a little boy, and it has been the running theme of our lives. We have indeed overcome.

India-inspired Poetry

Ishaan Holloway*

THE HEALING POWERS OF MY RUDRAKSH

(Inspired by the Mahadev Kala Temple, Shillong, Meghalaya)

The tears fall very prominently,
 The tears leave an auspicious mark,
 The tears form rare precious beads,
 Beads that have healing power like no other.
 The magic of the beads unfolds,
 The wearer is mesmerised,
 The magnificent beads bring calmness and serenity,

Such is the power of Rudra and his Akash.
 That is my Rudraksh!

THE MAJESTIC HIMALAYAS

The majestic Himalayas!
 Tough as stone,
 "Very beautiful", your impression is.
 But fragile, too.
 So let us work to preserve your beauty for humanity,
 To give to future generations to enjoy.

"Ishaan is a sixteen-year-old boy with severe regressive Autism. He is non-verbal, and he communicates (and writes poetry) by spelling things out letter by letter on a keyboard. He spent a number of years in the school system, but it didn't work at all, so we've been home-schooling him for the past four years. One thing we have found is that he is a very eager writer. He has his poetry published. Moushume, his mother is from India, and these two poems were inspired by things she has talked about with Ishaan."

— Ian Holloway, Ishaan's father

More about Ishaan on:

<https://nursing.ucalgary.ca/news/nursing-student-shares-her-experiences-working-child-severe-regressive-autism?fbclid=IwAR0g3PYOUuoo0hiStcqt7ijohjTfyJ9Sb1yUZ4fNiZc4nO9oRVQqLw5KU>

Fragile Not Broken

Shalini Kedia

Fragile X is a family of inherited conditions that can pass down silently through generations. Usually, a family gets to know about it when they have a child affected and diagnosed with Fragile X Syndrome.

The first book I read on Fragile X had my head spinning. Not having an interest in science or medicine, I always thought chromosomes, genes and DNA were just synonyms. A deep dive into the condition and 18 years later I know it all very differently.

Fragile X is the leading inherited single gene cause of intellectual disability and autism worldwide. It is caused by changes on the FMR1 gene located on the X chromosome. These changes can lead to the gene shutting down and hence stopping production of FMRP which is essential for brain development. Fragile X syndrome can affect males and females. It is a spectrum disorder and can affect individuals differently.

Symptoms:

- Delayed development
- Speech delays
- Intellectual disability
- Autistic features
- Sensory processing disorders
- Anxiety
- ADHD

Physical Features:

- Strabismus
- Frequent ear infections
- Long face
- Protruding ears
- Large forehead
- Prominent jawline
- Hyperflexible joints

Women who carry the premutation of the FMR1 gene have a 50-50% chance of passing it onto either

of their children. Also, 20% of the female premutation carriers can have a low ovarian reserve and difficulty in conceiving. The above story encompasses the most important take home messages regarding Fragile X Syndrome.

A woman who is experiencing fertility problems, a low ovarian reserve, low AMH and high FSH should be screened to check if she is a carrier for Fragile X before starting any fertility treatments.

The FMR1 gene responsible for Fragile X was only discovered in the year 1991 and that is quite recent in the medical world. The many facets of how the changes on the gene impact individuals have been unraveled over time. While there is not yet a cure for Fragile X, there are many treatments which can help an affected child. An early diagnosis leads to timely intervention and that can hugely impact the prognosis.

In 2010 a leading newspaper had covered an article on Fragile X Syndrome and it was quite detailed including symptoms, red flags, treatment options etc.

The next day I got a call from a father from Mumbai saying that he suspects that his 10 year old son who is on the spectrum might actually have Fragile X Syndrome. As our conversation progressed, I learnt that the mother had gone through 10 years of IVF because she was having a problem conceiving. This rang a bell and I organized to send the child's blood for testing. The results usually take 4-6 weeks. It came positive. This child had Fragile X Syndrome, but was missed because of the subtle differences and similarities between Autism and Fragile X Syndrome. Once he received the new diagnosis his treatment and management changed and that resulted in a huge positive growth for the child and the family. It is hence essential to look for Fragile X Syndrome if a child has been diagnosed with Autism Spectrum Disorders.

While there is no cure as of today for Fragile X Syndrome, an accurate diagnosis, early intervention and treatments bring hope for a better prognosis.

Treatments would include therapies, home programs and also medication which when put together make a huge difference.

Lack of FMRP heightens anxiety in children with Fragile X Syndrome. This anxiety can be a huge hurdle in their learning. In the above stated child's story, getting a diagnosis of Fragile X Syndrome changed his and the family's life. He was often pulled up at school for bad behavior and hitting. Many times sent back home too. His aggression was getting out of hand and at times he hit his parents too. Once diagnosed with FXS he was immediately

put on anti-anxiety medication. His therapies now focused on teaching him to manage his anxiety and calm down. His family would be careful to not trigger his anxiety too. Everything put together, the diagnosis was a blessing for this family.

We at the Fragile X Society of India have helped around 1400 families in all these years. Sometimes it is just explaining all of the above in simple lay man's words. Other times we connect them to other families in their same city and that's a huge support for them.

Though the condition is called Fragile X, in reality it makes families more resilient. We have experienced a bonding over adversity and hence I choose to say "Fragile not Broken"


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मेरे ऑटिस्टिक बच्चे से कौन शादी करेगा ?

मारीपत रेविसन

जब पिछले साल जॉन और मैं दक्षिणी अन्तराष्ट्रीय ऑटिज्म सम्मेलन में दिल्ली थे, यह सबसे अधिक बार ऑटिस्टिक बच्चों के माता-पिता द्वारा पूछा गया सवाल था। अमेरीका में सबसे पहला मुझे पूछा जाने वाला सवाल है। “मेरे बच्चे का क्या होगा और वो स्वतंत्रता पूर्वक कैसे रहेंगे?” अगर मुझे भारतीय समाज में शादी की महत्वपूर्णता की समझ नहीं होती, तो मैं इस अन्तर से बहुत चक्कर में पड़ जाती।

मेरे लिए भारतीय माता-पिता का यह सवाल भारत में पारिवारिक समाज की सुन्दरता को दर्शाता है। यह दृढ़, विस्तारित और भरोसे के योग्य है। पैतृकचिन्ता मुख्य रूप से अकेले रहने की नहीं थी, क्योंकि एक बार शादी, मतलब वहां पूर्ण रूप से परिवार होगा। मैं सोचती हूँ यह प्रशंसनीय व सुन्दर है, और मेरी इच्छा है कि ऐसा यूनाईटेड स्टेट्स में भी होता।

पर इस सवाल पर वापसी: “मेरे ऑटिस्टिक बच्चे से कौन शादी करेगा” ? इसका जवाब देने का एक ही रास्ता है मेरे अनुभवों का योग एक विशेष बच्चों की मां, मेरा बहुत से ऑटिज्म प्रभावित परिवारों का अवलोकन, *Neurodiversity* की महत्वता की समझ और एक नारी/औरत जो एक ऑटिस्टिक पती के साथ खुशनुमा दाम्पत्य जीवन में बंधी हुई है।

पहला मुझे यह कहना होगा कि अगर मेरी सासू माँ से (जिनको मैं उनके कुछ महीने पहले गुजरने के बाद उन की कमी महसूस कर रही हूँ) जान के वयस्क होने से पहले यही सवाल पूछा जाता तो उन्होंने शायद यही कहा होता कि “मुझे नहीं लगता कि उसकी कभी शादी होगी”। यह उनका जवाब होता इसलिए नहीं कि वो जॉन को प्यार नहीं करती परन्तु इसलिए क्योंकि उनका पूर्ण रूप से कुछ भी अनुमान नहीं था कि वो किस प्रकार का आदमी बनेगा।

ऐसा होने के असंख्य कारण हैं। पहला, उनके जॉन के साथ बचपन की मुश्किलें जो उनका और परिवार को उसके “अलग होने” के कारण अनुभव करनी पड़ी थी। बेशक यह पचास साल के पहले था, जब ऑटिज्म के निदान, सहयोग या ऑटिज्म के विशेषताओं की जानकारी नहीं थी। फिर भी जॉन की माँ का उसको जन्म देना उसकी समाज की उम्मीदों को पूरा करने में मुश्किलों के सन्दर्भ में था। यह जबतक जॉन एक व्यसक नहीं

हुआ तब तक वो उसकी तंत्रिका सम्बन्धी अन्तर की सरहाना नहीं कर पायी। (ऑटिज्म की)

दूसरा विकासात्मक विलंब वाले लोगों के जीवन के रास्ते को देखना हमारे लिए मुश्किल होता है इसलिए उन्हें विलम्ब कहा जाता है। दुनिया के बाकी लोगों की तरह ऑटिस्टिक समय बीतने के साथ सीखते, बदलते और विकास करते हैं। हम यह देख सकते हैं कि अगर हम जिन तरीकों से उन्हें बदलना चाहते हैं कि उम्मीदें छोड़ दें और उनके असली और अलग प्रकार के विकास की सच्चाई को अपना लें।

इस बात पर विचार करें कि डॉ. स्टीफेन शोर के माता-पिता को विशेषज्ञों ने उन्हें संस्थानीकरण के लिए कहा था। परन्तु उनके माता-पिता ने स्वीकारा की वो ऑटिस्टिक है और उनकी विकलांगता को कम करने के लिए और उनकी विशेष रुचियोंको दूँढने में अपनी पूर्ण शक्ति से सब कुछ किया। बचपन में अशाब्दिक, डॉ. स्टीफेन शोर एक प्रसिद्ध ऑटिस्टिक स्वयं अधिवक्ता है, जो दुनिया भर में घूमकर ऑटिज्म स्पेक्ट्रम में चालू और बन्द हजारों लोगों को आशा और किरणकेन्द्र दे रहे हैं। वो खुश दाम्पत्य जीवन में बंधे हुए हैं। कल्पना कीजिए की क्या हुआ होता अगर उनके माता-पिता ने विशेषज्ञों की नकारात्मक सोच को स्वीकार कर उन्हें एक संस्थानमें डाल दिया होता।

फिर यहां एक जेकब बारनेट की कहानी है। 1998 में यू.एस में जन्मे, बारनेट के माता-पिता ने उनके खुश और उज्ज्वल बच्चे को अलग-थलक अशाब्दिक बच्चे में परिवर्तन होने की विनाशकारी पीड़ा का अनुभव किया। उन्हें 2 साल की उमर में मध्यम से अधिक ऑटिज्म का निदान मिला। डॉक्टरों ने उनके माता-पिता को कहा कि शायद वो कभी बोल व पढ़-लिख नहीं पायेगा। आगे उन्होंने यह भविष्यवाणी भी की कि वो जूते बांधने जैसी बुनियादी गतिविधियों तक का बिनामदद के प्रबन्धन नहीं कर पायेगा।

जेकब के माता-पिता ने वो सब कुछ सीखा जो वो ऑटिज्म के बारे में सीख सकते थे। और डॉ. शोर के माता-पिता की तरह उन्होंने उसके प्रकटहुए पीछे हटने के विरुद्ध कड़ी लड़ाई की। विभिन्न उपचारों के साथ-साथ उन्हें एक सामान्य

बचपन का अनुभव जिसमें खेलने के अत्याधिक मौके देने की हर कोशिश की गयी। उनकी खगोल शास्त्र एवं जनित की विशेष दिलचस्पी को प्रोत्साहन दिया गया।

जब जेकब आठ साल के हुए तो इंडियाना यूनिवर्सिटी पर डीयू यूनिवर्सिटी की गणित कक्षा में बैठने लगे, परन्तु वो कहते हैं कि उन्होंने सामान्य रूप से बोलना तबतक नहीं सीखा जबतक वो 12 साल के हो गये। आज जेकब उसी यूनिवर्सिटी में शोधकर्ता एवंसम्मान (हौनर) विद्यार्थी है। और उनके शोध का विशय क्वंटम यांत्रिकी (Quantum Mechanics) है।

अपनी टेडटाल्कस, भूल जायें आपको क्या पता है, जेकब बारनट मूल रूप से कहते हैं कि जबकि ऐसा लगताथा कि वो दीवार को घूर रहे हैं और बोल नहीं रहे हैं, वो असल में भैतिक विज्ञान के बारे में सोच रहे होते हैं और अपने दिमाग में गणितीय सूत्र लिख रहे होते हैं। क्या ऐसा अन्य बच्चे जो मौखिक नहीं उनके साथ भी हो सकता है।

जेकब यह भी कहते हैं कि वो अचानक एक दिन ऑटिज्म से ठीक होकर नहीं रह गये। उनकी अभी भी कुछ मुश्किल है जिन पर उन्हें हर रोज काबू पाना है।

हमें कभी नहीं पता होता है कि कौन कैसा निकलेगा। जब मैं दसियों साल पहले जाज से मिली थी जब मैं अब से बहुत अलग थी। मैं कम परिपक्व थी, राय बनाने में जल्दबाद और समझने में धीमी। संक्षेप में मैं अभीतक ऐसी जिन्दगी से प्रभावित नहीं हुई थी जो मुझे एक ज्यादा दयालू और प्यार करने वाले दिल की रचना करने के लिए लागू होगा।

इसके विपरीत, जॉन अपने वयस्कता के पुरुआत में कैसा था? उस समय जॉन आंख से संपर्क बनाने में कम था। अब वो यह ज्यादा कर सकता है। जॉन तब किसी भी कपड़े पर लगे लेबल को जो भी हो बर्दाश नहीं कर सकता था, अब उसकी इसमें ज्यादा सहनशीलता है। जॉन मूवी देखने नहीं जा सकता था, भीड़ के सामने बोल नहीं सकता था, अब वो किताबें लिख सकता है, शेर-शराबेवाले खाने की दुकान पर ठहर सकता है, ऑटिस्टिक लोगों के सामाजिक न्याय नेतृत्व कर सकता है, अथवा और बहुत सारी चीजें कर सकता है, जो अब कर रहा है। मैं उस पर बहुत गर्व महसूस करती हूँ।

क्या वो अभी भी ऑटिस्टिक है ? बिल्कुल और आज मैं इसके ऑटिज्म के साथ की गई विशेषताओं की प्रशंसा करती हूँ। मैं यह पूरी तरह से नहीं करती हूँ, परन्तु मैं उतना करती हूँ जितना हमारे सम्बन्ध को प्यारा व मजबूत बनाता है।

जो परिवार गंभीर विकलांगता से लेन-देन कर रहे हैं उनके प्रति मेरी सहानुभूति और समझ है। जब मेरी बेटी तीन साल की थी और उसको दौरे पड़ रहे थे, मैं निराशा से अभिभूत थी। फिर भी जब एक बार मुझे उसकी विकलांगता से कैसा व्यवहार करना है कि ज्ञान और सूचना प्राप्त हो गयी, और फिर उसके सकारात्मक गुण पर फोकस करना प्रारंभ किया तो मुझे अब और निराश नहीं थी। मेरे अनुभव से स्वीकार करना, जानकारी व कार्य निराश के मारक हैं।

इसलिए मैंने अभी कहा कि मैं जॉन के ऑटिज्म की प्रशंसा करती हूँ और वो इसलिए क्योंकि मैं उसके कुछ ऑटिज्म लक्षणों के साथ की अच्छी चीजें भी देख सकती हूँ। और यह अच्छी चीजें क्या हैं ? यहां एक आंशिकसूची है।

- जॉन विश्वसनीय है और सच बोलता है।
- जॉन मेरे जानकार दयालू लोगों में से एक है।
- जॉन शंतिपूर्ण है और आपत्ति लेने में धीमा है।
- जॉन प्रतिभाश ली है खास कर अपने विशेष रुचियों में।
- जॉन विश्वसनीय है और उसे स्थिरता पसन्द है।
- जॉन बहुत मेहनती है और फोकस करके रह सकता है।
- जॉन दयालु है।
- जॉन मजाकिया है और मुझे हंसाता है।
- जॉन दूसरों की जिन्दगी में एक फर्क डालता है और उन्हें आश दिलाता है।
- जॉन एक बढ़िया सौतेला पिता है।
- जॉन की तार्किक सोच बहुत मददगार है।

एक और सवाल जो मुझसे पिछले साल भारत दौरे पर पूछा गया था: क्या हमें संभाव्य परिवारों को बताना चाहिए कि मेरे बच्चे को ऑटिज्म है। यह एक अच्छा सवाल है, क्योंकि ऑटिज्म स्पेक्ट्रम निदान के साथ कलंक सम्बन्धित रह सकता है। जैसे कि मैं यह कभी सिफारिश नहीं करूंगी कि कोई अपनी पहली नौकरी के इन्टरव्यू में अपने ऑटिज्म के बारे में बात करे, क्योंकि वो नियोक्ता द्वारपक्षपात से उन्हें तुरन्त खारित कर सकते हैं, और असलियत में नौकरी से जुड़ी योग्यताओं का मूल्यांकन किये बिना। इसके बदले में उन्हें अपनी उन विशेषताओं के बारे में सोचने की सलाह दूंगी जो उन्हें काम में विषिष्ट होने में मदद कर सकते हैं और उनके बारे में बात करें।

जान और मैं बहुत साल तक उसके ऑटिज्म के निदान के पहले से दोस्त हैं। शयद इस चीज ने मुझे उस इन्सान की तारीफ करने में मदद करी जिसमें सिर्फ 'सनकी' समझती थी। अपनी यात्रा के दौरान में इतने सारे लोगों से मिलती हूँ

जिनके बच्चों को ऑटिज्म का निदान मिला है, और जैसे जैसे वो इसके बारे में और पता करते हैं, उन्हें यह विश्वास होने लगता है कि उनकी भी पत्नी स्पेक्ट्रम पर हैं, बस निदान नहीं मिला है। मैं सोचती हूँ कि यह हमारी पीढ़ी के लिए बहुतसामान्य है।

जबतक मुझे जान के ऑटिज्म के बारे में नहीं पता था मैं यह कभी नहीं माना कि हमारा प्रेमपूर्वक सम्बन्ध हो सकता है, क्योंकि मैं उसकी कम वांछनीय विशेषताओं (जैसे की अपने बारे में लगातार बात करते रहना) ही उसकी सम्पूर्ण व्यक्तित्व था, बजाय उसकी ऑटिस्टिक न्युरोलॉजिकल वायरिंग का। मैं आश्चर्य में थी कि वो मेरी कम वांछनीय विशेषताओं के बारे में क्या सोचता था, जैसे की मेरा एडीएचडी (ADHD)। परन्तु उसके ऑटिज्म का शुक्रिया उसने शायद ही कभी उस पर ध्यान दिया। अथवा ऐसा जो वो कहता है।

हम जिस दृष्टि से अपना संसार, अपना परिवार और खासकर अपने बच्चों को देखते हैं इसमें सकारात्मक तरह से फोकस करना बहुत महत्वपूर्ण है। हम अपने बच्चों को जिस तरह से देखते हैं वह उन्हें खुद को देखने का आकार देता है। उन्हें पता होना चाहिए कि हम उनकी ताकतों की सराहना करते हैं। इसका मतलब यह नहीं है कि हम उनकी विकलांगता को नकार दे, उसके बदले हम उनकी मुश्किलों में सहयोग देने के तरीके ढूँढें, जैसे कि महत्वपूर्ण, उनकी ताकत बढ़ाने के विकास के अवसरों में सहयोग दें।

जब हम किसी से कुछ जो हम उनसे करवाना चाहते हैं करवाने की कोशिश करते हैं, क्या हम यह नहीं कहते हैं कि यह कितना अच्छे से हो सकता है। बजाये कि कितना खराब? हम जब भी अपना बेस्ट कदम आगे बढ़ाते हैं तो हमेशा परिस्थिति में अच्छाई देखना ही समझदारी होती है। और वो आखिरी बार कब था कि निदान करने वाले ने हमें हमारे बच्चे के ऑटिज्म के बारे में सकारात्मक पहलू बताये? यह कोई आश्चर्य की बात नहीं है। हमें इस बात को बुरी तरीके से महसूस कराने के लिए तैयार किया जाता है।

मैं किसी के ऑटिज्म के बारे में झूठ बोलने की वकालत नहीं कर रही हूँ। परन्तु मैं निश्चित रूप से यह सुझाव दे रही हूँ कि एक इन्सान उसे निदान कि या लेबल से अधिक होता है और सबसे अच्छा है कि अगर हम नकारात्मक से अभिभूत ना होकर सकारात्मक चीजों को देखें। मैं किसी को भी आमंत्रित करके उन सकारात्मक चीजों की सूची बनानेको कहूंगी और उनके बारे में सोचने का अभ्यास करें। और इस नकारात्मक सोच पर काबू पाने के लिए अभ्यास की जरूरत है क्योंकि यह

हम सब करते हैं। हमलोग शायद एक जाति की तरह बने नहीं रह पाते। अगर हमारे पास यहां करने के क्षमता ना होती।

सकारात्मकभाव की सोच को जारी रखते हुए, इस बात पर ध्यान दे कि इस सूची में अधिकतर लोगों का अनुमान लगाया जा रहा है कि वो उनको एसपरजन सिन्ड्रोम है, मुख्य रूप से उनकी दूसरों से अलग सोचने की क्षमता। यह संसार उनके बिना क्या होता ?

- मार्कजूकरवर्ग, फेसबुक के संस्थापक
- बिलगेटस, माईक्रोसॉफ्ट के संस्थापक
- जेने आस्टज, लेखिका
- माईकलऐनजिलो, रेनेसाथ कलाकार
- लडविग वैन बीथोवन, संगीतकार
- एलबर्ट आइनस्टीन, भौतिक विज्ञानी
- ऐलिकसैन्डर ग्राहम बेल, टेलीफोन के आविष्कारक
- बिन्सेत वानगोह, कलाकार
- आइसेक न्यूटन, गणितज्ञ व भौतिक विज्ञानी
- सतोशी तजीरी, पोकेमोन का आविष्कारक

अगर हम अपने ऑटिस्टिक को इन्सानियत के एक ऐसे क्षेत्र के रूपमें देखें जिन्होंने समाज को फायदा दिया है, हमारे पास हर इंसान के निहित क्षमता को प्राप्त करने का मौका है। ज्ञान शक्ति है और स्वीकारता शान्ति लाती है, जो हमें मजबूत नाकि कमजोर बनाती है। इस विचार से लड़ने के बजाय कि हमारे किसी चाहने वाले को आटिज्म है, हम कार्य कर सकते हैं, और कार्य संसार के हर परिवर्तन को चलाता है। हमें अपने अलग होने की माफी नहीं मांगनी है। चलो हम इसमें से अधिकांश बनाये, और शायद यह सवाल हो जायेगा: "मेरे ऑटिस्टिक बच्चे से शादी करने के लिए कौन उसके लायक है" ?

वक्ता, लेखिका, कवि, साधक, आरोग्य करनेवाली, स्पेशल शिक्षा और ऑटिज्म की समर्थक, भूतपूर्व मीडिया कार्यकारी और सम्पादक, मां, बीबी, मारिपट राबिस जो बहुत सारी टोपियां अभिमान से पहनती है तो न्यूरोडाईवर्सटी आंदोलन को सहयोगदेती है और विश्वास करती हैं कि व्यक्ति क्या कर सकता है (बनिस्बत क्या नहीं कर सकता) पर फोकस करना ऑटिज्म जागरूकता, स्वीकारता व प्रशंसा का अगला कदम है।

I Married a Geek कि लेखिका – एक मजाकिया इतिहास उनकी जान एल डररविसन के साथ जिन्दगी, जो दुनिया के एक अग्रसर ऐसपी है। वो एक लोकप्रिय व्यंगपूर्ण ब्लॉग भी इसी नाम से लिखती है।
(<http://maripatrobinon.blogspot.in/>)

AFA MEMBERSHIP FORM

Action For Autism(AFA) is a parent organization that strives to create an environment where individuals with autism and their families can live as fully participating members of the community.

To support AFA to further its mission, please complete the form below and return to: Action For Autism, The National Centre for Autism, Sector 7 & 8 JasolaVihar, New Delhi 110025.

Name _____

Address _____

City _____ State _____ Country _____ Pin/Zip _____

Phone _____ Email _____

I am a: *(Check all that apply)*

Mother Father Other (please specify) _____

Professional: Name of Organisation _____

For Parent of a person with autism ONLY:

Child's Name _____ Gender: Female Male Date of Birth _____
dd mm yr

Diagnosis _____ Diagnosis received from _____

I wish to become a member of AFA. Enclosed is a contribution *(Check as applicable)*

Via: Cash Online Demand Draft (in favour of Action for Autism, payable at New Delhi)

Online Transaction/Draft No _____ Dated _____ Drawn on _____

Amount in Words _____

Annual Membership Charges: Parent: Rs. 500 Professionals: Rs. 1000 Institutional: Rs. 3000

Online bank transfer may be made to:

Beneficiary: Action For Autism

Bank: Vijaya Bank, Defence Colony, New Delhi, India

SWIFT No: VIJBINBDDCD

IFSC Code: VIJB0006005

MICR Code: 110029007

Savings A/C No: Within India Transactions: 600501010009008

Oversees Registrations: 600501550010210

All contributions are tax exempt under Section 80 G of Income Tax Act.

Please use the following link for the AFA Membership Form:

https://docs.google.com/forms/d/e/1FAIpQLScCMXDWrFPAZyFSNEVvsPHXBhpzm38soamnIm0srGokpEes5Q/viewform?usp=sf_link



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