

Nav-ratri with an Extra Chromosome

These days we get lot of Whatsapp gyan on each festival and event. This time is also no different. There have been strings of messages explaining significance of every day, color associated with it, gods, and demons and so on 😊

For me this Nav-ratri is special as my son, Shlok has stepped in his 9th year recently. Shlok is a down-syndrome child. Now he is fairly independent with decent progress at school including writing alphabets and numbers etc. In normal course of life, it is not a big deal. Though for special parents it means loads of happiness and hope of steady progress...

It has been a special journey from “why us” helplessness on the day of Shlok’s birth to “Yes, We can” mindset today. Shlok was born on 6th Aug 2009 and merely in 12 hours we were informed that he is a down’s baby and due to un-even heart-beat he needed to be moved to Level-3 Neo-natal ICU of Texas Children’s Hospital in Houston (USA). With God’s grace he came out ok in 3 weeks. But those 21 days were bleakest days of our lives...

Over the years, Shlok has enriched and transformed our life in many ways. During new-born to toddler days my wife, Sheetal had to work hard patiently with early-intervention team of medical professionals so that Shlok can reach smallest of the mile-stones that other normal kids reach without any efforts. Surprisingly Shlok’s mom took it in stride better than me. The process of imparting basic life-skills to Shlok, has helped us appreciating smaller things of life with humility. We may not be able to visualize him as highly educated or super-successful individual. Yet we can thrive on smaller; incremental successes that we can cherish along the way...

Down syndrome kids tend to be right-brain individuals and given proper support they can do well in all kinds of artistic works. I am glad Shlok was born in USA and we were able to get the objective information about his condition in first couple of years as possible (It is hard to explain people the difference between a disease and a condition!). One such learning was reading Chris Burke’s biography which gave a good count of how a down’s kid from New York went on to become TV actor in a best known series – “Life Goes on”. It was certainly encouraging...

As he grew old past toddler years with his imperfections, we got to experience variety of people perceiving him differently. Especially, we came across in-adequacies of educational systems in India. Apparently India has been shining since advent of 21st century. Yet utter insensitiveness towards differently-abled kids in ultra-polished cookie-cutter chains of private schools is a glaring reality. On other hand, there are very few special schools with good facilities or practically no integrated schools that would help special kids to reach their true potential...

Eventually, with good fortune, Shlok is going to a small private pre-primary school where teachers take genuine efforts for child’s true growth and imparting learning. Also we have been lucky to get guidance of activists and educational volunteers/professionals who have been working for the betterment of special kids. Small network of fellow parents of special kids have been a dependable support along the way. Still we have a long way to go as in developed countries, there is fairly good

network of parent support and advocacy groups in all major cities. They push the envelope right from immediate psychological support to new special parents to influencing government policies for special families in various aspects of life...

In the early days of returning from USA, I had opportunity to visit factory of “Associated Manufacturing” in Chakan, Pune; a unit of automobile pressed components. Currently there are more than 35-40 special individuals working in a traditional manufacturing set-up. Despite their shortcomings, their work is precise, neat and would beat average production numbers on any day. The story of Subhash ji Chuttar and his son, Ajay Chuttar is heart-warming. Ajay is young man who overcame innate dis-advantage of down-syndrome and currently working in family business. This first-hand experience surely inspired and gave me courage to keep up and hope for a better tomorrow...

With the exception of handful compassionate souls, I see in-sensitiveness is rooted across our society for all dis-advantaged individuals at some level or other. In this ultra-fast age of androids and drones, special kids allow us to be bit more kind and considerate than what we are. Shlok is a die-hard positive and kind-hearted child. He has mastered art of handling rejections from his peers every now and then. Still he would approach his friends without any hesitation. Of course, Shlok finds permanent friends in his little brother, Vivaan and cousins. He just embraces each moment with full of life and innocence. That reminds me all-time classic movie-“Forrest Gump” featuring Tom Hanks as ever-innocent Forrest...

In general, Down Syndrome kids are very social and nat-khat (mischievous). On many occasions, Shlok would disappear in a crowd within a blink of eye and we would end up searching him. Most of the times we found him within short-span of time. Still those few moment were heart-wrenching at best. Learning from this, we put on a small locket with Shlok which mentions my phone number and aadhar number etc. Of course, the next mile-stone is when he is independent enough to carry himself around safely in our community and neighborhood...

The emotional journey for me and my family has been challenging and will be so in future as well. The continued support from immediate and extended families and friends has been surely a blessing along the way. The journey has helped us expand our minds to numerous possibilities than just being “normal”; isn’t that “special” in itself. Life works in a mysterious ways which cannot be fathomed with human intelligence. Perhaps, difficult situations present “collateral beauty” that I hope to see and do something meaningful for these individuals/families at large...

Navratri/Dussehra is an extended celebration of goodness. Shlok is our special celebration with “full-of-life” spirit and with a push of an extra chromosome... Life is good !!!

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