

## Looking ‘Down’ to myths and opinions- World Down Syndrome Day

*By Dr. Shruti Bajaj, The Lifestyle Portal Online Writing Program student*

*March 21st is celebrated as World Down Syndrome Day. Here is an article by one of our students on busting the myths of children with down syndrome.*

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Down syndrome is one of the most common causes of intellectual disability, across the globe. The worldwide incidence of Down Syndrome is pegged to be somewhere around one in every 700 liveborn. Extrapolating the figure to an exploding Indian population of 1.2 billion (and still counting), the burden of children with Down Syndrome in our country is mammoth! While some of us may know about this condition, it is very likely, that all that we know is not right.

On the upcoming occasion of World Down Syndrome Day, celebrated globally on 21st of March every year (21.03.2018; 21st chromosome, 3 copies), I take the onus upon myself to dispel the fog around this condition, and create some clarity and awareness about this ‘not-so-rare’ disease.

### **Why does Down syndrome happen?**

Our human bodies have the ‘blueprint information’ for normal functioning, stored in each cell in the form of super coiled-up structures, known as chromosomes. We all have 23 pairs of chromosomes residing in each cell. These chromosomes are numbered sequentially by the scientists in the order of their size when they are stained and tested, the largest chromosome numbered as 1.

If my handset number is hypothetically 66 55 77 88, and if someone dials 666666 55 77 88; the person will fail to connect. Similarly, if a person’s body harbours three copies of chromosome 21, instead of two, some error in the signalling is expected. This is to put it simplistically, as to what is the mechanism at the cellular level in individuals with Down Syndrome. An extra copy of chromosome 21 means an extra dosage of the genes (functional units of the hereditary material) present on it.

This error is most commonly attributed to normal biological processes gone awry in mothers with an advanced age, though there are other causes too. It is wrong to believe that only older mothers can give birth to babies with Down Syndrome. In fact, a majority of the children with Down Syndrome are born to

women lesser than 35 years of age; reflecting a higher birth rate in women of this age group.

### **How does Down Syndrome manifest?**

Classically, individuals with Down Syndrome have been described as having cognitive delays, learning problems, structural cardiac disorders, endocrinological concerns, medical concerns with the eyes and the hearing, complaints with the digestive system, joint and spine laxity, and growth issues. They are also prone to early onset memory losses (sometimes as early as 40 years of age), cancers, and immunological diseases and sleep disorders.

### **What are the myths surrounding Down syndrome?**

It is of paramount importance to note, that not all the individuals with Down Syndrome will have all of the above the features; definitely not in the same severity. Just like all of India is not about slums and Taj Mahal; all of Down syndrome isn't about being intellectually challenged and 'different looking'!

While these individuals do have certain similar physical characteristics, it is untrue that they all look the same. In fact, if one looks closely, a person with Down syndrome resembles his own family members more than another person with Down syndrome from another family. I once complimented an unknowing and chuckling infant with Down Syndrome, "Ah! You have got your mother's smile!", only to witness a broader, prettier and more confident smile by the mother herself!

Most people stereotype individuals with Down syndrome. To clarify, not all of them have a severe intellectual disability. Though these individuals have cognitive delays (ranging from mild to severe), the IQ alone is not truly and totally reflective of their individual capabilities. If given the right opportunity, early stimulation and comprehensive medical care, along with a favourable environment at home and school; these individuals can lay impressive goals as to how to define 'success'.

These kids are overall more social and interactive than other children having cognitive impairments or learning disabilities (due to other causes, like, say autism). However, it is wrong to believe that all individuals with Down syndrome are always happy-go-lucky (and no, it's not necessary they all HAVE to love music). They too have their range of human emotions and feelings, their good days and bad ones; their own distinct personality. In the same nerve, it is wrong to believe that these individuals are always sick. With improving medical care, these individuals manage to live a healthy life; albeit with more frequent health visits and some intercurrent illnesses.

Most children with Down syndrome benefit from education and training that is integrated with mainstream learning, 'along with other kids', rather than that from institutionalised and special schools.

### **Are there any success stories of individuals who have Down syndrome?**

Right from perusing a Bachelors in Psychology, to playing seven musical instruments and being a guest to none other than Oprah Winfrey, to owning a high-end restaurant, to being a sports champ; there is little that some of these 'special' individuals haven't achieved.

It would be unjust to expect every child with Down syndrome to do all or any of the above, but these examples are to highlight that the human spirit and human capabilities cannot always be 'prognosticated' based on just an extra copy of a chromosome.

### **Why did I choose to write on this topic?**

Ultimately, it is the parents' prerogative to take a decision regarding the continuing of a pregnancy diagnosed as having Down syndrome. As Clinical Geneticists, we offer the 'complete picture' to the family and empower the parents to take further decisions. While the write-up doesn't intend to flare up the controversy (more relevant in the West, as of today) regarding the abortions of fetuses having Down Syndrome, it intends to make the reader more familiar with the complete clinical spectrum and the good part of the story (most often ignored) along with the bad (we tend to know that faster and better, somehow).

I will end the write up with clarifying one last myth. Down Syndrome is named after Dr John Langdon Down, who first described this medical condition and its cause. A parent once asked me, "Is it that this condition is called Down syndrome, as an antonym to Up? Signifying that my child is little less privileged, little less of an achiever, in any way?" Calmly nullifying the thought and bruising a hurt esteem due to the countless prejudices faced in her day-to-day life; I firmly told her a NO. After sharing the truth of how the condition gets its name, I suggested, that your child may be Down, but he is never OUT!"

### ***About our student:***

Dr Shruti Bajaj is a Consultant Clinical Geneticist at Cloudnine Hospital, Mumbai. She's one of our esteemed students at The Lifestyle Portal Online Writing Program.

Paediatrician and a Qualified Clinical Geneticist (a very rare breed of Clinicians/super-specialists who help patients out with clinical evaluation of suspected genetic disorders and deal in genetic counseling, especially in terms of improving the existing quality of life of an affected individual and preventing a recurrence of the disease when applicable).

Dr Bajaj has spent 17 years at the very prestigious Seth Gordhandas Sunderdas Medical College and King Edward Memorial Hospital, Mumbai; acquiring from here not just her insane passion for the field of Clinical Genetics, but also her basic (MBBS) and advanced (MD Pediatrics) degrees, followed by a University accredited Fellowship in Clinical Genetics. This period included a 4.5 years' rich

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clinical experience as a Faculty & Assistant Professor in the Department of Pediatrics & Genetic Clinic at the same Institute.

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