

'JAYA' of Mind over Bones!

Shubha R Phadke

Department of Medical Genetics, Sanjay Gandhi Postgraduate Institute of Medical Sciences, Lucknow, Uttar Pradesh, India

Correspondence to: Dr Shubha R Phadke Email: shubharaophadke@gmail.com

We think bones are the strongest part of body and cannot be easily broken. I doubted this once again when Jaya and Vijaya (names changed) came to meet me. I had seen them for the first time more than a decade ago on television shows singing songs and talking about their 'incurable' illness with smiling faces. They are very small, less than 3 feet in length (yes, 'length' as their 'height' cannot be measured) but have 28 years experience of life which is full of pain due to recurrent fractures. Their bones are so fragile that they fracture on touching. Their bones are not even seen clearly on radiographs. The long bones are seen as just wavy lines, and the bends cannot be counted. 'Ashtavakra' (a man with eight bends- a character from Indian mythology) had a crooked body due to the curse of his father who cursed Ashtavakra before he was born because he corrected mistakes in his father's recitation of the Vedas from his mother's womb. Ashtavakra may have been a case of osteogenesis imperfecta. Jaya and Vijaya also had fractures in fetal life and the bones were bent at birth. However, unlike Ashtavakra's father, their parents would never have wished for this, but the defective copies of the gene were transmitted one each from the normal parents. Jaya and Vijaya are twin sisters with a severe type of osteogenesis imperfecta. Not just eight, they may be having more than 80 bends in their bodies and though not the Vedas, they sing Bhajans (devotional songs) in their sweet voices. The sweetness in their Bhajans comes from their hearts. Their hearts are pure and large. They sing, draw pictures and are creative. They cannot stand or walk, but their eyes dance.

Disability and pain have not been able to stop them from being happy and creative. Probably, the artists in them are flourishing as a response to the harsh reality and physical challenges posed to them by their disorder. Thanks to their parents, who have similar smiling faces, the girls have been brought up with positivity and desire to conquer

the world. The girls have met Prime Ministers and Presidents of India, have been presenting their talent on television shows, and have had the opportunity to sing with famous singers. Their achievements are remarkable. It is much more than what most of the tall, fit and intelligent people in the world have achieved. What is most striking is the purity of their heart and soul. They do not have complaints about their 'God-given' ailments and neither do they have grievances against their condition. They have no sense of competition or jealousy. Their minds are beautiful and they spare no efforts to look beautiful as well. Lipstick on the lips, nail-polish on the nails, rings on the fingers and colourful dresses make them look pretty. The credit goes to the parents and their strength of mind which they have probably inherited from their parents in addition to the *CRTAP* gene mutations.

They are on bisphosphonate therapy for the past ten years. Their pain has decreased and now they can sit. Visits to the hospital are infrequent as they are often travelling for various cultural programs. I get to meet them once in a few years. The phone calls are frequent. Sometimes I feel reluctant to respond but as soon as I pick up the phone, the sweet voice asks, 'How are you?'. I get calls from many patients and their families but hardly anyone asks my wellbeing as the first question. The love in their voices touches my heart and the bubbling enthusiasm puts positivity in me. I stop bothering about my own problems. However big my problems seem to me, they are actually miniscule in front of the hardships of Jaya and Vijaya. Seeing them, I am reminded of the fact that 'Being Happy' is a choice that does not really depend on the presence or absence of problems and successes. The lives of such patients and their families are big lessons for all of us and teach us coping strategies and instill in us the spirit and strength to fight against adversities in life.

The causative genetic defects for genetic dis-

orders of the bones, heart and brains have been mapped. But where is the mind – in the brain or in the heart? Can we image their minds which are stronger than the bones of any body builder? Can we do molecular mapping to see the positivity of their minds? If possible, we should identify sequence variations for their positivity and strength of mind and make molecules to be used as miracle drugs. Hope someday this may be possible! Bisphosphonates for strong bones and 'MINDosphonate' for strong minds. Till the molecules are available, everyone should follow role models for happiness like Jaya and Vijaya. Just being around them brightens your day as happened just yesterday in our outpatient department (OPD). During the three hours in our OPD, while waiting for the tests getting done, both of them sang Bhajans surrounded by all patients who

enjoyed the sweet voices of the little angels and forgot their pains and problems for some time. Both the girls too enjoyed the attention, though sitting for hours at a stretch was too taxing for them. We all felt touched by their divinity. I always feel lucky to serve patients and learn from them about medicine and life.

Note:

Jaya and Vijaya were gatekeepers of Vaikuntha Loka, the abode of Lord Vishnu (the 'God of Preservation and Protection' in the Hindu Trinity).

'Jaya' also means victory in Sanskrit and Hindi.

The girls will be proud to share their original names, but the names have been changed in accordance with medical ethics.

For the detailed story of Ashtavakra, see: <https://en.wikipedia.org/wiki/Ashtavakra>