

## **Epilepsy, Endurance Sports and Social Interactions- My tryst**

I am Vinay Jani resides in the heart of India, New Delhi. I'm an Ultra Randonneur, 4 Times Super Randonneur, a Marathoner and attempted Paris-Brest-Paris in 2019.

In July'2005 was diagnosed with focal seizures due to a cyst in the left temporal region of my brain. This affected my lifestyle and daily routine in a massive way. To cure this situation, I tried various medication from Hemopathy to Ayurveda but nothing helped.

In December'2008 my seizures graduated to a generalized seizure due to which I was hospitalized for few days and when I was getting discharged my neurologist said "I'm prescribing you medication which is not as per your weight now it's up to you whether you increase your medication dosage or you want to loose weight". I had gained weight during that period as I was not aware how manage epilepsy. This made me realise the urgency to loose extra kilos.

Slowly and gradually, I restarted my workouts at the gym near my home and there was no looking back to the past. After having no seizures for 5 years my neurologist decided to withdraw my medication and after 1 year, I had recurrence of seizures so I met neurologist again my medicines were resumed but this time I preferred to take precautions rather than keeping myself under restriction and I kept going to gym but informed by friend to keep an eye on me whenever I'm doing workout with weights. Later on, I started joining group classes of indoor cycling too in gym. In 2015 I met a trainer and he asked me to join him for outdoor cycling.

I declined the offer as it was risky to do outdoors rides with epilepsy. But immediately he said that he will ride along with me. After that there was no looking back for me.

After three months I bought my bicycle and Gautam added me to cycling group SpinLife where mostly riders use to do endurance cycling and wearing a Road ID band was a norm in the group. In May'2016 I did my first brevet of 200km and all my co-riders were aware that I'm a person with epilepsy so I had a company through-out my brevet in fact my every brevet which I have done till date including Paris Brest Paris. Brevet is concept of endurance cycling which is originated from France through Audax Club Parisian and in India it is conducted by Audax India Randonneurs. Though I abandoned Paris Brest Paris at 473kms marks but every failure comes with a learning and I'm looking forward to re-attempt the 2023 edition.

After coming back from Paris, I started running too with Adidas Runner – Delhi and signed up for Airtel Delhi Half Marathon and I started taking training for running. After my half marathon my trainer featured me on social account through which I got connected to another Marathoner and writes blogs for own passion for writing but after meeting her I realized that even after earning in endurance sports I'm missing something. That 'something' was to help other people with epilepsy to manage their epilepsy and to evolve in any kind of physical activity but before taking a step further I preferred to take advise from my senior rider and mentor who clearly advised me to write motivational write-ups only and then there was no looking back and I started writing on my social handles. In January'2020 an article was featured on me The Hindu followed by another feature in The Asian Age and I was also felicitated by Sir Sachin Tendulkar just a day before my Marathon. During lockdown I started looking for NGO's who are working for people with epilepsy are interaction become much easier for me and in Epilepsy Awareness Month my blog was featured on Living well with Epilepsy and I shared my blog my neurologist Dr. (Prof) Manjari Tripathi and she

immediately advised me to be a speaker on a webinar with Sir Jonty Rhodes which was conducted by Indian Epilepsy Society and become a member of epilepsy support group Ekatwam.

Whenever we start doing some work which is in welfare of the society it comes with the responsibility. When government gave some relaxations in lockdown most of the marathons went virtual way and having experience of the same, I gave an input of Virtual Walkathon to Samman Association - Mumbai during 50 Million Steps for Epilepsy campaign which they executed in very organized manner. Presently I'm raising funds for Child Raise Trust through my participation Tata Mumbai Marathon 2021 which will be utilized for medicines for underprivileged children with epilepsy.

Endurance sports taught me discipline, patience, hard work, learning from own mistakes but interacting with people taught me joy of giving.

Vinay Jani