

Health adversity manifested into a gift !!

Science has been spectacularly powerful but there are times when even the best of doctors seem to struggle to find a cure to specific ailments. Today, I would like to introduce **Rachit Shah**, an

ex-Investment Banker from Mumbai who is passionate about **spreading awareness on rare diseases**, and has a lot of interesting things to say!



Hi Rachit, tell us how your journey started ?

Firstly, I would like to thank you for this opportunity.



Revisiting the dark tunnels of my memory, it was a horrifying evening walk in 2016 that changed my life, when I got trapped into leg cramps with an aggravating pain in the lumbar region.

My night was painful and unaware that my encounter with time had just started.



A plethora of clinic-aid investigations was done before I got diagnosed with a rare disease called **Isaac Syndrome** (a diverse disorder as a result of muscular hyperactivity resulting in muscle cramps, stiffness, walking difficulties, fasciculation, fatigue), accompanied by **Membranous Glomerulonephritis** (a slowly progressive disease of the kidney), **Lymes** (a bacterial infection that can be spread to humans by infected ticks), and **Glaucoma** (an eye conditions that damage the optic nerve often caused by high pressure).

The diagnosis was followed by extensive therapies like **Steroids**, **Plasma exchange**, **ACTH injections** etc..... **38 pills** were a part of my daily acid tasting platter accompanied by many food restrictions when regular episodes of IBS, diarrhea, body pain, weakness & muscle loss were claiming rights over me. Fluctuations in general-stats like sugar levels, BP, weight etc... surfaced pendulous effects.

I had to make changes in my wardrobe as weight melted off, from 80kgs to 57kgs. It's unbelievable how I didn't feel hungry post-lunch until 8 am, the next morning.

Though my journey has been a sketch of mixed-bag with a **180° transformation** from a cultural, social, economic, and health repute, I've come a long way from being bed-ridden in 2016 & 17 to being almost independent today. Now my food-habit-curve shows signs of normalcy, and the clouds of skepticism have withered with a sure-shot reduction in medicinal intake.



It was over a hearty breakfast with my doctor at his residence in Jaipur when

I decided to pen down articles, a conscious effort when I realized that even Google was ignorant while answering my queries.

When did you decide to write ??



Not many people think the way you do; what inspired you to take this initiative as a one man army ?



As Bear Bryant once said "In a crisis don't hide behind anything or anybody. They're going to find you anyway" therefore I took the challenge by shifting the doctrine of focus towards **Positivity**, as conquering tough situations is not only about physical stability but involves great mental health as well.

Though there were many trials and errors, all the struggle has seen me grow and raised my bar of confidence to emerge from unexpected difficult situations. This is not only about my journey but **coming together for a cause** as a voice taking ownership to infuse awareness.



WHO defines a rare disease as often debilitating lifelong disease or disorder with a prevalence of 1 or less, per 1000 population.

Can you brief us, what a rare disease is ?



However, different countries have their own definitions to suit their specific requirements and in the context of their own

population, the health care system, and resources. These '**Casanova typed diseases**' need special lenses as symptoms are diverse leading to cases being under or misdiagnosed.

'**The National Health Policy for Rare Diseases**' acknowledges the annual cost of some treatments may vary from Rs 10 Lakhs to more than Rs 1 crore/yr.



Healthcare for rare diseases is our human right therefore inviting wisdom from Organizations/Institutions/ Patients and Support groups could be helpful in reducing our burden as

bailout is not an option but a compulsion.

Thank You again !

Any last thoughts before we end ?

You can reach me at rachitshah421@gmail.com.

