

## ISN Patient Stories

850 million people globally live with some form of kidney disease. We are delighted to share the stories of Siva Kumar Raghavan to raise awareness of the patient experience.

### **Siva Kumar Raghavan, international speaker and athlete, Malaysia**



I am the eldest of 4 siblings. All my family members are healthy and we have no family history of Chronic Kidney Disease. I have always been an active, adventurers person and an entrepreneur in nature.

I was never been sickly nor been admitted in hospital until I was diagnosed having Chronic Kidney Disease in 2008, when I was only 38 years old. The cause of my kidney failure was Immunoglobulin Nephritis A(IgA) . For the next 3 years till end of 2011, I was maintaining myself very well by controlling my protein diet and being conscious of my eating habits.

Sometime in early 2012, I was introduced to a Korean algae product that was claimed to cure chronic kidney diseases and believed to even reverse it back to normal. Being hopeful and desperate, I did not hesitate to miss this golden opportunity save myself from this misery. Unfortunately it turned to be total opposite. My kidney worsened drastically that year from the creatinine being 180 to 1200 in 6 months.

In January 2012, I was given immediate attention by my Nephrologist and started dialysing as soon as possible. I then opted for CAPD (Continuous ambulatory peritoneal dialysis) for 6 months.

My wife and I were consulted by our Nephrologist to do a living related Transplant. We were the first to do Spousal Living Related ABOi (different blood group) Transplant in Malaysian Government Hospital. The Transplant were instant success and I was up and running in just 5 months. Due to the ABOi Tx, I was given high dosage of Immunosuppressant to manage my antibody. However just after 2 years, I was experiencing gradual increase in my creatinine. My kidney was slowly weakening. After few test, it was confirmed that the affect was by BK Virus. I was immediately admitted and given several veils of costly vaccines imported from Europe. Thankfully the virus was attended promptly and my Transplanted kidney was saved for now. After this incident, my immunosuppressant was reduced. Two years later, I was again experiencing increase in creatinine and this time it was fatal. My Transplanted kidney couldn't be save and I was back to dialysis in September 2016.

Meanwhile, during all these episodes of Transplant were happening from 2012 to 2016 , I took charge of becoming the President of Malaysian Transplant Association (Green Ribbon Support Association) comprising of 300 over Transplant Recipients (Kidney, Liver, Bone Marrow and Heart). I brought a group of Transplant recipients to Asian Transplant Games in Bangkok where I won bronze medal for 5km walk competition. We also did send few of our members to World Transplant Games in Rio and UK.

After my journey started as a dialysis patient, I knew my chances of getting a cadaveric organ for Transplant were very slim due to the sad state of statistics converting brain death to potential organ donor in our country. I started to join hands with few enthusiastic Nephrologist cum practitioners like Dr Ghazali Ahmad, Dr Rosnawati and Dr Sunita in making Transplantation a success in Malaysia.

As a patient myself, I am determined to live my life to the fullest by being role model to my children and other fellow dialysis patients. I started doing active hiking and I successfully climbed several mountains in Malaysia. Despite my limitations of having to do dialysis every other day, I plan my climb strategically so that my dialysis is not compromised and I get to experience the adventures that I desire.

I truly hope I will get a chance to be Transplanted soon so that I can live quality life longer with my loved ones. I have a beautiful loving wife and 2 adorable children, son is 12 and my daughter is 8.

*July 5, 2022*  
**Siva Kumar Raghavan**