

ISN Patient Stories

850 million people globally live with some form of kidney disease. We are delighted to share the stories of Manvir Victor and Verónica Martínez to raise awareness of the patient experience. You can also read more patient stories in this article produced for AstraZeneca by BBC StoryWorks Commercial Productions and presented by NCD Alliance as part of the Facing Forward series.

Manvir Victor, patient advocate and media figure, Malaysia



Manvir Victor, the editor, broadcaster and patient advocate, had no idea he was at high risk for kidney disease until he received his diagnosis at 34.

“The doctor said my creatinine levels were dangerously high and my kidneys had deteriorated to the point of 75% – which meant that it was irreversible,” he says from his home in Malaysia. His first doctor told him he had to go for dialysis immediately, but after seeking more medical advice, Victor held off for a few months.

“A lot of people didn't understand how I had gotten ill so quickly,” he says. “I was fine, I was playing sports, back then I was a radio DJ, I ran the number one radio program in the country.”

“Everything came to a shuddering halt,” says Victor. “When I started my dialysis in February 2002 I weighed about 86kg. By the end of the year, I dropped down to about 70kg. The illness hit me quite badly, both physically and mentally, to a stage where I couldn't walk 100m without stopping.”

In 2012, his wife donated a kidney, and while contact sports like football are ruled out, he now goes to the gym, swims, runs and cycles every day.

In 2002, there were no patient organisations that Victor could join, and he felt isolated as a result. This encouraged him to speak to other patients when he returned to hospital for checkups. Now, Victor is the WHO chairman for patient safety in Malaysia, a member of the National Patient Safety Council and part of the British Medical Journal international patient panel.

Verónica Martínez, lawyer, Mexico



Born with only one kidney, a condition called renal agenesis, Veronica Martínez's challenges with her health started young. At 12 months old, she was diagnosed with vesicoureteral reflux which was causing infections in her urethra. By the age of seven, the infections had returned, and on the advice of her doctors activities like gymnastics were off the cards. Martínez says she found it hard to interact like other children.

Then the kidney infections returned at 17 and lasted through her education, resulting in about three hospitalisations each year, until she travelled to Madrid for her Masters' degree. “It was pretty hard

because you're at the best age when you only want to be with your friends and going out and traveling," says Martinez. "And again, it was the second time when I had to deal with the frustration of not being able to do everything that my friends were doing."

While in Spain, a sense of independence and self-care moved her to seek medical advice and found proper treatment that improved her health and her quality of life ever since. She also met a friend, who is a doctor, who became a life-long source of support.

"If I could go back in time, I would tell myself to not be afraid and just give in to the experience of what life has put in my way," says Martinez. "And that if I am brave enough to do it, I will be amazed by my own self and find amazing things for this second opportunity in life."