The Threads in My Blood

My name is Arpit Chopra, and I carry something in my blood that I didn't ask for. Something invisible, but relentless.

It is called **hereditary transthyretin amyloidosis**—hATTR for short.

A rare genetic disease that weaves itself through generations like an unwanted thread in the fabric of a family.

I was 35 when I began to feel the first signs. At first, I blamed work stress and too much coffee. Numbness in my right calf. Pins and needles in my toes. Exhaustion that clung to me no matter how much I slept. Then came the weight loss I couldn't explain. Then the gut problems, the dizziness, the unpredictable blood pressure.

It took 3 years of misdiagnoses, tests, specialists, and frustration before someone finally said the word "amyloidosis."

When they added the letters "hATTR," it changed everything.

This disease doesn't just affect your body. It rewrites your sense of self. The mutation in my **TTR gene** causes misfolded proteins to build up in places they shouldn't—my nerves, my heart, my digestive system and my eyes. I lost almost 28 kgs of weight in 3 years. I have undergone vitrectomies in both my eyes to remove amyloid deposits; now I'm developing cataracts in due to previous vitrectomy surgeries. My worst symptom is my polyneuropathy which has meant I am no longer able to walk independently or drive my car.

The impact of the disease took a toll on my personal life as well.

I was once happily married, now being divorced in middle of this battle as my wife struggled with my diagnosis. Fortunately, I have an 8-year son who loves me and is proud of me the way I am fighting this disease.

When I was eventually diagnosed in 2022, I did my own research about treatments in Australia and I learned of an amyloidosis clinic at Box Hill Hospital in Melbourne, run by Dr Simon Gibbs.

Attending the AAN clinic in Melbourne changed my life forever.

Dr. Gibbs promised me that he will do everything possible to get me the right treatment. He suggested that I join Australian Amyloidosis Network, follow them on Facebook and attend the AAN's educational workshops. I have gained so much knowledge from these sources.

In 2022, there were no approved treatments for hATTR Amyloidosis in Australia except for some off label drugs like Diflunisal, an old anti-inflammatory similar to tafamidis but with more side-effects. Due to the advocacy of the AAN,

there were several clinical trials of new treatment for hATTR in Australia. I chose to participate in the amyloid-depleter drug trial called AT-02 in 2023.

I received the best Christmas present on 23rd December 2023.

Dr Gibbs called me saying I have been approved for compassionate access to an FDA approved drug Patisiran which had shown excellent results to slow the progression of the disease by decreasing production of the amyloid-forming TTR protein. Accessing Patirisian would never have happened without the AAN advocating for me to Alnylam, the makers of Patisiran. Dr Gibbs even travelled to Zurich to lobby for free drug on my behalf and several other patients.

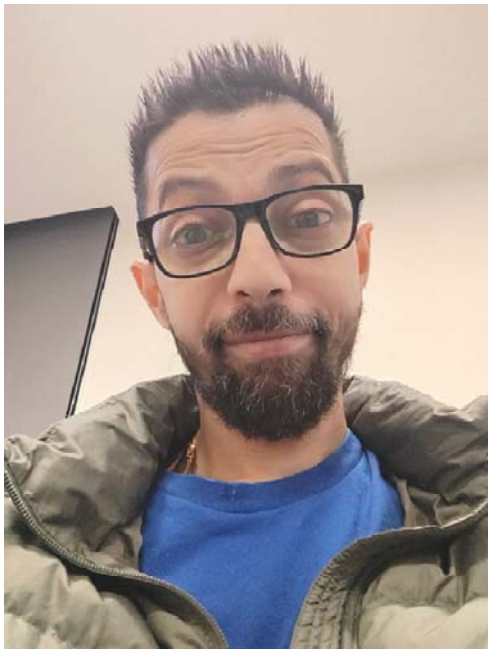
My first infusion happened on 8th February 2024 and fast forward to May 2025, I feel much better. My looks have changed, I have gained some weight and my gut function has improved a little bit. While my neuropathy has progressed, it is now at a much slower rate.

Some days, I feel like a burden.

I need help getting dressed. I walk with a four-wheel walker. There are nights I lie awake wondering how this disease came to me. I am the first one to be diagnosed in our 3 generations of our family.

But I also fight.

I'm lucky to live in a time when committed health care professionals and patients work together in the AAN to help ensure patients in Australia get the best quality care possible. Treatments are finally emerging. Gene silencers. Stabilizers. Therapies that slow the cascade. They don't cure me—but they give me time. Time to watch my son grow. Time to tell my story. Time to matter.



There are still losses. I used to be one who was always out exploring. Now I measure my days in steps, in symptoms, in careful planning.

Living with hATTR is like being chased by something slow but steady. It never stops. But neither do I.

I've learned to cherish what doesn't hurt. To find light in a day with less pain. To laugh even when it

aches. And to hold my family closer than ever—because in the end, it's not the disease that defines us. It's what we do with the time we have.

And I choose to keep going.

Please donate to the AAN.

Given that there are more people diagnosed than ever before, the AAN cannot continue the amazing work they have done for me and hundred of other patients without your financial support.

I would not be alive today if it wasn't for the AAN - I want to keep going and I want other patients to keep going like me.

Arpit