

Leading a normal life seven years after diagnosis

For Neel Kankani, a jute exporter living in the Indian city of Kolkata, the figure 172 is what most people would call a lucky number. It was printed on a sheet of paper that would save his life.



Neel was among the first group of patients in India to begin treatment in April 2002 with Glivec, an advanced cancer medication produced by Novartis. Two years earlier, he had been diagnosed with CML (chronic myeloid leukemia), a rare and usually fatal bone marrow cancer.

In September 2000, Neel had been running a constant mild fever, around 99.5 degrees Fahrenheit, and had lost his appetite. He visited his family doctor, had blood tests and other analyses, and quickly learned the bad news.

“Whenever you hear the word ‘cancer,’ that is always scary – the fear that you won’t be able to live long,” Neel recalls. “That was the reaction of all my family members. We looked on the Internet for more information about CML treatment, and it was not encouraging. I could see that my life would be ending.”

But toward the end of 2001, Glivec became available in the United States (where it is known as Gleevec) after being approved by the US Food and Drug Administration in May. The drug was not immediately available in India, so Neel traveled to Pennsylvania for diagnosis. “I was excited about this new medication, but I knew it was not affordable to me,” Neel recalled. “So I went back to India. Then I heard about the Max Foundation.”

The foundation had been selected to operate the Novartis Glivec International Patient Assistance Program (GIPAP) in countries around the world. Supported by Novartis, the foundation makes available Glivec to needy patients at no charge.

So in April 2002, Neel received a form with the number 172 confirming that he had been accepted into the GIPAP program in India, and began treatment with Glivec. “Within a few months, the disease went into remission,” he said. “There was initially some fluid retention, but that was managed with proper eating, and now I don’t have any problems. I can say that I’m leading a normal life.”

Neel, now 33, had been married only three years when he was first diagnosed, and his daughter was only a few months old. Now she is seven and has a three year-old brother, born after Neel began treatment with Glivec.

They consider themselves a normal Indian family. Neel travels overseas two to three times a year and works long hours, but on weekends the family enjoy being together – going out for dinner, watching a movie or just window shopping. They take active holidays, and Neel enjoys swimming and play volleyball or cricket. “Nobody knows that I have a disease,” he says.

Neel has become active with the Max Foundation, which holds regular patient meetings in cities around India where patients can learn more about their disease, share experiences and provide support to others. The regional dialect in Kolkata is Bengali, which is not spoken in many other parts of India, so Neel helps patients to communicate with each other. “I tell patients who are newly diagnosed not to be worried,” he says. “They are very lucky that this medicine is available now, and there is a lot of help available.”

Neel believes strongly that if pharmaceutical companies like Novartis cannot obtain patent protection for their medications, eventually research and development will suffer. “If companies spend billions of rupees on research, and anyone can use their formulas, then why should they bother?” he asks. “They are spending a lot of time and money. But if this stops, then there won’t be any new treatment for life-threatening diseases, or new diseases.”

After being treated with Glivec for almost five years, Neel is grateful to Novartis and the Max Foundation, but almost matter-of-fact about his own condition. He compares himself to a diabetes patient whose disease is controlled through insulin. “Until Glivec, the normal life span for somebody with CML was five or six years,” he says. “But for me, it’s not a life-threatening disease any more.”