



www.hcvadvocate.org

# living with HEPATITIS C

---

a series of stories written  
by people living with  
hepatitis C

---

## Sanjiv

### Part 1: Living with Hepatitis C and Heart Disease

#### Motivation to Share My Story

*A wise old man once said “Disease is what you have and illness is how you react to it.” Most patients share their experiences after they have had successful outcomes; I would like to share mine as I traverse this journey with the hope that I might inspire a few of us (out of the 180 million infected worldwide with HCV) who are finding it tough to cope with situations or are losing the will to fight. I hope my story touches a chord or two and provides emotional support and encouragement.*

*I do not know the outcome of this long, arduous, test of endurance and spiritual strength; but what I do know is that after three and a half years of being on therapy for HCV (3 attempts, having taken 190 shots of pegylated interferon, consumed thousands of ribavirin tablets and undergone a heart bypass surgery during this period) I have the “motivation to fight” with the hope that I have a chance of getting cured.*

#### The Discovery

Prior to my diagnosis with HCV in March of 2005 I was a happy, active 45-year old man. I worked hard and played hard – my hours were always filled with various activities. I was motivated, outgoing and well-adjusted. It seemed that I “had it together.”

In 1989, at age 30, I had been diagnosed with heart disease and underwent a successful “quadruple” heart bypass surgery. This is when I contracted the hepatitis C virus as I was given blood transfusion during heart surgery. The HCV was *discovered* in March 2005. This meant that I was HCV+ for almost 16 years prior to being diagnosed.

My body had begun manifesting trademark side effects prior to discovery. Ultimately, these side effects became so overbearing that it dawned on me that something was radically wrong. I started losing energy; I felt nauseated and fatigued all the time; I was not sleeping well. My liver enzymes turned out to be very high (ALT 160, AST 105) and a PCR revealed that I was HCV positive. Moreover, I was

Genotype 1 (the one difficult to treat) with a very high viral load of 2.7 million copies per ml. My liver biopsy experience was horrible; the doctor who performed the biopsy was not skilled with the needle and I had to be poked five times, which was very uncomfortable. When the results came they showed that my liver had been extensively damaged and I had fibrosis stage III (bridging fibrosis), a stage prior to liver cirrhosis. With all odds against me, it was a foregone conclusion that I should start HCV treatment.

### **My First Attempt**

I started therapy for the first time in June 2005 and continued till May 2006 (50 weeks). I took the first brand of pegylated interferon plus 1000 mg of ribavirin. I became HCV negative in the first 12 weeks, had a viral breakthrough sometime later and at the end of therapy I was diagnosed positive.

From everything I have heard, read and researched, each person's journey on treatment is personal and will differ from others. I have not been spared the debilitating side effects of anemia, irritability, muscle aches, nausea, vomiting, low-grade fever, weight loss, insomnia, hair loss, depression, anxiety, mood swings, fatigue, dry skin, itching and rashes.

In regard to my work (I own and manage a consulting company in India) – my plans required major adjustments – the treatment caused me to be extremely tired and not able to deal with the typical day-to-day issues of a running a successful company.

### **My Second Attempt**

I restarted therapy in May 2006 and continued till June 2007 (57 Weeks). This time I shifted to the second brand of pegylated interferon plus 1000 mg of ribavirin. Once again, I became HCV negative within 12 weeks and stayed negative till the end of therapy. I had planned to continue therapy to 72 weeks but I had to abandon my plan in the 57th week as I required a repeat heart bypass surgery in July 2007. While recovering from the surgery I relapsed

and the HCV virus rebounded to a very high level of 16.7 million copies per ml.

This was a massive blow for me, and, as is well-known, troubles in life come in pairs. Patients who fail interferon-based treatment typically have few or no treatment options, and are at risk for progressive end stage liver disease. In a recent study, the risk of liver failure, cancer or death following unsuccessful HCV treatment is 23% after 4 years, and 43% after 8 years.

### **My Third Attempt**

Without giving up hope and still wanting to fight, I had to do something different compared to what I had done in the first two attempts; if I did the same thing yet again how was I to expect a different result? After consulting with the best in the field of liver disease in October 2007 barely 4 months after my heart surgery, with renewed vigor and HOPE, I decided to give it another attempt. This time my plan was a higher induction dosage of interferon and ribavirin and a longer duration of 72 weeks.

I started therapy for a third time in October 2007 with the second brand of pegylated interferon. For the first 24 weeks I was on 200% of regular dose and 1200 mg of ribavirin. Then for 12 weeks I tapered it down to 150% of regular dose and 1200 mg of ribavirin, thereafter and at present, I am on the regular dosage and 1000 mg of ribavirin. I have completed 44 weeks in my third attempt. I plan to continue therapy for a minimum of 72 weeks. My body weight being only 54 Kg (the average American patient is 75 Kg) my system is heavily taxed. Higher doses of interferon and ribavirin give higher rates of adverse events. I continue to have my share of side effects which include nausea, fever, malaise, myalgias, fatigue, abdominal discomfort, mood swings, cough, irritability, skin rashes, pruritis, constipation, sleep disturbances, mouth sores, etc. There are days I am progressively fatigued and feel a lack of energy and there are days I feel complete debility and I want to remain in a closed shell of my

own. However, staying involved with a routine of healthy habits, family and a work routine helps me tremendously.

## Support System

As I reflect on my life, I believe that I am “truly blessed” by the almighty in that I have been saved every time before disaster has struck. At age 30, I was diagnosed and treated for heart disease before I had a heart attack. Then again, while going through the second attempt at HCV therapy I was diagnosed and retreated before I had a heart attack; a heart attack would have been fatal and would have cost me a lot including my life or it would have left me dilapidated and not strong enough to participate in this marathon!!... In fact, even when I was diagnosed with HCV in 2005 my prognosis would have been much worse if I was discovered to be co-infected with HBV and HIV or if liver cancer had set in. I consider myself very fortunate that today I am in a position to be hopeful and am able to participate in this marathon.

Other than blessings, the almighty has given me a fantastic support system in my lovely wife Kavita (a doctor by profession), my parents and my two lovely children Rohan and Raghav (picture below) and many many well wishers. I have learned the attributes of a positive attitude from my father, the virtues of believing in God and prayers from my mother and commitment from my wife. My family is my motivation to continue.

## My Condition at Present and My Daily Routine

As I write this, I have completed 44 weeks of my third attempt at therapy; my liver functions are normal and I am virus negative, I am

anemic with a hemoglobin Level of 10.2; my white and red blood cells are very low. My platelets are normal. My body weight is 54 Kg. Other medical parameters are normal.

Each attempt went by slowly at first and then moved into an eventual rhythm. I work to ensure that I get out of the house each day and force myself to follow a healthy routine. I begin each day with a morning walk, in addition I practice yoga. I also have a masseuse who comes over twice a week. I eat a simple, low fat diet. My routine is invaluable in helping me deal with the treatment side effects. I have also begun to meditate each morning – which helps me accept my circumstances and face each day with a level of zest, hope and joy!

A natural diet, low in saturated fat, refined carbohydrates, animal proteins and high in fiber is recommended. Eating foods rich in lecithin, essential fatty acids (flax oil) and green leafy vegetables rich in antioxidants are all gourmet cuisine for the liver. Alcohol is a complete ban. A nutritional supplement that includes vitamin C, Vitamin B, Folic Acid and Milk Thistle is recommended.

My tryst with HCV will continue and I don't know for how long. If all goes as per the plan I will complete 72 weeks of the third attempt at therapy in March 2009. I may extend the therapy on a “lower maintenance dosage” and will pray that I do not relapse. There are major medical breakthroughs (Vertex oral protease inhibitors) expected by 2011

and in a worst case scenario if I do not achieve success prior to 2011, I still have hope . . . to “beat” the virus in my fourth attempt with the new generation drugs.

I am grateful to the long list of medical professionals who have patiently addressed my questions and provided



me with the best advice: Prof Mitchell L Shiffman, Dr Bennet Cecil, Dr Samir Shah, Dr Sanjiv Saigal, Dr Subhash Gupta, Dr S K Sarin, Dr Navin Dang, Dr Desmond Wai, Dr Sanjiv Sikka, Dr Kavita Syal, Dr Naresh Trehan (my two time heart surgeon) and my Yoga Guru Vijay. I am grateful to the websites HCV Advocate, Clinical Care Options and Janis for enriching my knowledge on the subject and the work they do for the community. Above all, I am eternally grateful to the mastermind of it all - the almighty GOD!!

What I have gained from life in 49 years is far more than I have lost in the past three and a half years of side effects, mental turmoil and quality of life compromises. The discipline, the will to fight, the ability to understand what is important and what is not are my virtues. I am in control of my life and health and I am mentally at peace. I have learned the facts and determined the best way to proceed. I believe that God's hand, my family's love and my own endeavors will keep me going. The best advice I can give to our community is to "think positive, keep the faith and hope, enjoy life in the present moment, take treatment each day at a time and believe in God"!!

My email is [sanjivsyal@ablindia.com](mailto:sanjivsyal@ablindia.com), and I will be very happy to share more details.

*"Hope is both the earliest and the most indispensable virtue inherent in the state of being alive. If life is to be sustained hope must remain, even where confidence is wounded, trust impaired." Eric Erikson*



## ***Be Sure to Check Out These Other Stories***

- Alan's Story
- Brian's Story
- Carol's Story
- David's Story
- Dee's Story
- Gerald Moreno's Story
- Jake's Story
- Jason's Story
- Kathleen's Story
- Leslie's Story
- Martha's Story
- Mike's Story: Part 1
- Rosa's Story
- Twila's Story

[www.hcvadvocate.org/community/stories.asp](http://www.hcvadvocate.org/community/stories.asp)

**For more information about hepatitis C, hepatitis B and HCV coinfections, please visit [www.hcvadvocate.org](http://www.hcvadvocate.org).**

*• hcspFACTsheet •*  
A publication of the Hepatitis C Support Project

<b>Executive Director</b> <b>Editor-in-Chief, HCSP Publications</b> Alan Franciscus	The information in this fact sheet is designed to help you understand and manage HCV and is not intended as medical advice. All persons with HCV should consult a medical practitioner for diagnosis and treatment of HCV.
<b>Design</b> Paula Fener	
<b>Production</b> C.D. Mazoff, PhD	This information is provided by the Hepatitis C Support Project • a nonprofit organization for HCV education, support and advocacy • © 2008 Hepatitis C Support Project • Reprint permission is granted and encouraged with credit to the Hepatitis C Support Project.
<b>Contact information:</b> Hepatitis C Support Project PO Box 427037 San Francisco, CA 94142-7037 <a href="mailto:alanfranciscus@hcvadvocate.org">alanfranciscus@hcvadvocate.org</a>	

 **HCV ADVOCATE**  
[www.hbvadvocate.org](http://www.hbvadvocate.org)