



**Hepatitis B Foundation**  
*Cause for a Cure*

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www.hepb.org

The Hepatitis B Foundation (HBF) greatly appreciates Joanna James' personal story about living with chronic hepatitis B and for allowing us to share her story with others at our *B Informed Patient Conference* this year. Below is an excerpt from her first letter that moved us to invite Joanna to share her journey with hepatitis B:

*"I realize that hep B is quixotic and everyone's situation is different. Still, it seems to me that one can help one's self quite a bit while waiting for a cure."*

*I would be delighted to allow you to share my experiences with others. In fact, I would invite anyone to write me with questions or experiences of their own. Though it seems quaint these days, I do not use a computer and do not have an email address." J. James*

**For those interested in writing to Ms. James, please feel free to contact us and we will be happy to share her postal address. She would value hearing from others living with hepatitis B.**

**We also invite others to share with their experiences in living with chronic hepatitis B to help us create an anthology of short stories (non-fiction) for print and/or online. Please include your name, address, email with any submissions, but know that we can publish your story anonymously if preferred. Thank you!**

**Contact Joan Block, Editor**  
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*"I Survived Hepatitis B ... Twice!"*  
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## **I SURVIVED HEPATITIS B .... TWICE!**



**By**  
**Joanna James**

**May 2006**

## **Onset**

In the spring of 1984, I noticed that a beer I was drinking tasted strange. About the same time I began to feel like something was pressing against my stomach. Gradually, I began to lose my appetite and thought, "Uh-oh, I'm coming down with the stomach flu." This went on for several weeks.

My job then was in a Texas institution for the mentally retarded where I worked as a nurse. My work routines began to seem burdensome and small things irritated me. Each night when I got home I was just beat.

In June of that year, when I had just turned 54, I scheduled a minor surgical procedure for a Friday, figuring that I'd be completely recovered and ready to go back to work on Monday. When Monday came and I hadn't recovered, I knew something was really wrong because I was a healthy person and used to bouncing back quickly. I went to see my doctor who thought I might have an ulcer. He asked for a urine specimen and I noticed how brown it looked. The next morning, my doctor called and gave me the news: I had tested positive for hepatitis B.

During report time at work, I told my head nurse and fellow nurses. The atmosphere in that room changed instantly. The nurses visibly shrank from me as though I were a leper and my head nurse, looking grave, said that I'd probably be off work for a long time. It was surprising how little we knew about the disease.

## **Illness**

My head nurse was right. It was fall before I was able to even consider going back to work. Despite the initial diagnosis of a "mild" hepatitis B case, I was literally unconscious for a good part of many days.

One day when we were in the grocery store, all my energy suddenly vanished, as though a plug had been pulled and it had all drained out. And so it went, week after week after week. I felt I was fighting some unseen enemy that was bent on my destruction. The uncertainty of never knowing when it would strike sapped my confidence horribly. It was like living at the end of a leash of indeterminate length so that I never knew when I'd reach the end and be unmercifully jerked back again.

Over time, through repeated bad experiences, I learned to store up energy by staying in bed a certain length of time before doing anything, and then to rest up afterwards. Normally, a person gets that "second wind" when the liver releases stored glucose into the bloodstream. That's what gives us stamina. With a damaged liver we don't have that reserve. When it's gone, it's gone.

## **Recovery**

The onset of hepatitis B, according to my medical dictionary, is described as "insidious" meaning "coming on gradually or almost imperceptibly". That definition could describe my recovery as well. It was two steps forward and one step back for about two years.

In October I returned to work. At first, I only worked a few hours at a time, just long enough to administer all the evening medications. Over the next six weeks or so, I gradually increased the amount of time I spent at work. However, it finally became apparent to me that I just wasn't up to the job any longer and I resigned at the end of November.

In December, my longtime partner Nick and I went to Mexico. We had no reservations, spoke almost no Spanish and sometimes walked long distances carrying our luggage. Despite these hardships, I will never forget this trip, for many reasons, both good and bad.

Shortly after the trip, my son's mother-in-law, who owned the house I was renting, passed away. Instead of leaving her property to her daughter, she put it in a trust fund managed by the bank. The bank then raised my rent 75%, which forced me to move out.

Moving, under the best of circumstances, is something I both dread and abhor. It would have been difficult enough, given my health problems, even if we had just rented another house in town. Instead, Nick and I bought a piece of completely undeveloped property 100 miles away. It had no utilities, no buildings, and was far out in the country on a badly rutted road. Only people as naïve as Nick and I would have undertaken such a venture, but that's just what we did.

To this day I do not understand how I found the strength to get through the months that followed buying this property. We first bought a trailer (the only house I ever owned) and had it moved out to the property. Living in a trailer was certainly a brand new experience for me. I spent many an anxious hour through storms

willing it not to turn over and crush us to death. When I say storms, I mean the most spectacular displays of lightning I've ever seen and rains so torrential they literally prearranged the landscape. Despite it all - with many days when I felt so crappy - I loved it there.

## **Big Chances**

By late winter of 1986, all of the romantic walks through fields of waist-high wildflowers, nights of star-gazing and the surreal feeling of living in a western movie were not enough to disguise how desperate our situation was beginning to be. The money was running out and Nick was spending more and more time with some less-than-savory neighbors.

When my daughter Valerie and her husband Dwight came to visit us in February, she was frankly worried about my condition but didn't say so. That spring I crashed. My depression became so acute that in desperation I called the suicide hotline in Austin.

This turned out to be one of the best decisions I ever made. I was directed to a place where I was evaluated. Though I cannot now remember who recommended a liver biopsy or why, I had one done. The diagnosis was "some inflammation" that seemed to be healing.

I was told that I had "chronic persistent" hepatitis B, and from what the doctor said, I was given to believe that the condition could gradually resolve over time. There was no treatment prescribed. I continued to take the vitamin and mineral supplements that I had taken for years, plus herbs that were supposed to be especially beneficial for liver health: dandelion root, tumeric and milk thistle.

Later that month I visited Valerie and Dwight in New York City. While there, we got word that my mother had died and that she had divided all the money evenly between my sister and me. I was frankly surprised that my mother left me anything, but it was a lifesaver. From then on my life began to change dramatically.

## **Moving On**

That summer I saw a notice in the paper about a course in Silva (self) Mind Control that intrigued me. It opened doors for me in bringing my awareness to my unconscious negative thinking and programming and taught me how to meditate. With this newfound

power, I decided to embark on yet another career. My nursing days were gone and I was open to something new that better suited my belief in holistic health and medicine.

I moved back to Austin and enrolled in a one-year program for massage therapy. This course exposed me to principles of Chinese medicine and to various forms of energy work. It also put me in a community of people who were there for me when my life with Nick began painfully falling apart.

From the time I started massage school, I was also getting massage therapy work done myself. It had the effect of letting me out of a cage that had imprisoned me my entire life. My self-confidence soared. I became increasingly interested in eastern religion and metaphysics.

During this time my family considered a move to the West Coast to open a bed and breakfast inn. When Valerie and Dwight bought a house in the Columbia River Gorge of Oregon, I planned to join them on the venture, knowing that I could contribute my skills of cooking, gardening and massage. It seemed like a dream come true: being able to work and live with my family.

In June 1989, at age 59, I moved to Oregon to manage the house until my family's arrival. I did not know one soul in Oregon, but the scenery was magnificent. That first summer, I began landscaping the property, painting deck furniture and doing more things to fix up my new home than I can list.

The following year, Valerie became pregnant after 12 years of marriage. The announcement shocked me to my knees. The dream I was living had come to an end before it began -- my family never did move to Oregon after all.

## **Relapse**

In June of 1992, Valerie and I took a trip to Washington State while Dwight took care of their toddler at the Oregon house. While we were on that trip, some old familiar symptoms began to reappear and I feared the worst; the hepatitis was coming back.

By late summer my liver enzymes were the highest they'd ever been and I was diagnosed with "chronic-active" hepatitis B. By then I was definitely sick. My date book for that time tells a dramatic story. There were lunch and dinner dates, house guests, massages,

classes, and various appointments almost daily up to July 9, 1992. After that there was nothing but blank pages. I sat in my chair. That's all I did. My doctor at the time was a naturopath and an acupuncturist. He told me, "You don't have to die from this." This was valuable to hear because my medical books painted a fairly grim picture for chronic active hepatitis.

Dr. S. told me that it was very important that I rest, rest, and rest some more. He put me on a very digestible diet and I had acupuncture treatments to balance my liver meridian. When he learned that the root of a native plant had antiviral properties, he told me to take that, too.

In October, I arranged to see a gastroenterologist from Portland. He examined me and noted petechia on my upper back and redness of my palms, which he said were signs of some liver damage. Neither he nor any doctor I had seen thought I had cirrhosis.

We discussed all the medical options available at the time, including interferon treatment. I decided none of them sounded right for me. For one thing, they were all very expensive, required frequent trips to the doctor, and could cause a worsening of hepatitis once the treatment had ended. He didn't discourage me from what I wanted to do: continue with my good diet and supplements and manage my energy as carefully as I could.

This last bout changed my body. I gained at least fifteen pounds and I could function only half of each day. Up until then I had looked and felt 15 or 20 years younger than I was. Now it was no longer true. I just never regained the kind of stamina for regular exercise classes, though I did (and still do) yoga at home.

### **Better Off**

One thing I love to do is writing. There was a period when I wrote daily and extensively in one journal after another. And I've always been an extensive letter writer. Now, sitting weakly in my chair, writing became my therapy and my salvation. I wrote essays. I wrote poetry, including Haiku. I wrote stories and recorded my dreams.

I also practiced mindfulness, noting what feeling I had when they came up, and paying attention to what made me tired and when was the best time for me to do things.

Since I had more energy in the morning, that's when I'd do

every active thing possible. I cooked practically all my food in advance, knowing that if I didn't, I would be living on sandwiches and candy bars, and not get the vegetables and grains and good things that I needed. I learned to break big jobs into a lot of small ones and not let things build up.

I've truly learned how much more enjoyable life is when you focus your attention fully one thing at a time. I've learned to space out whatever I have to do. If I'm very active one day, I might do more sedentary things the next. This takes planning ahead but it really helps me live on an even keel. So even with hepatitis, I'm probably better off as a whole than I was before.

### **Philosophical Outlook**

In the fall of 1989, with the Oregon house sold, I moved to Connecticut where I now live in my own apartment attached to Valerie and Dwight's house. I have constructed a rather extensive garden here and I have an enjoyable life. My last blood test showed my liver enzymes at normal range. I still take a nap most afternoons, but not always. This year, when I turned 75, I was finally able to give up smoking.

While I wouldn't wish hepatitis on anyone, I probably have the resources and temperament to handle it better than many could. It's natural to ponder what I might have been if I hadn't gotten the disease, but my philosophical approach is to look at what it has given me, not what it has taken away. I've learned to enjoy what I have rather than pining for what I don't have.

Life since hepatitis may be less wide but it is certainly a lot deeper. Getting hepatitis was not completely the end of my life, as I knew it, but the beginning of a new life -- one with different challenges, yes, but also with some special rewards. Who knows what the future holds? No life comes with a guarantee, does it?



**ENERGY**      **By Joanna James**

When a virus attacked my liver, an organ essential to my health,  
It stole my strength and stamina, insidiously, with stealth.  
It turned my body traitor, complete with foreign ways,  
And blew apart the world I know and left me in a daze.

Slumping weakly in my car, another's hands upon the wheel,  
Where my hands had been when I'd had nerves of steel.  
I marveled at how competent I'd been in June.  
Now here was I, in July, like a helpless limp balloon.

I shrank against the cushions and screamed aloud in fear  
At only 30 miles an hour, and each time a car got near.  
I felt so weak and fragile, utterly without defense,  
Not just in the car, but everywhere, devoid of confidence.

In autumn I rose in a hostile world, frail and exhausted to the bone.  
I struggled to recover the structured life I'd known.  
But thirst and noise, and even sun in which I'd love to bask  
Were now foes. Even eating became a task.

Each mistake in judgment would cost me days in bed.  
It seemed no matter how I tried, I could not get ahead.  
I felt threat from everyone, no matter how unjust.  
It's odd how having energy had enabled me to trust.

A like-afflicted man told how he'd searched for keys  
--his brother waiting in the van--  
Only to discover that he clutched them in his hand.  
Despair, he said, devoured him and he began to cry.  
"What's happening to me? Who the hell *am I*?"

I nodded knowingly, having learned how reason can grow obscure.  
Possessions hide, abilities fail, and a trusted world disappear.  
Confusion (or any change) could send me back to bed.  
I feared a major crisis could quite well leave me dead.  
\*\*\*\*\*

Slowly, slow remission came, though I didn't call it that.  
To me, it was recovery from a crash that had left me flat.

With strength returning, my mind began to churn with plans  
And renewed belief that, once again, I could handle life's demands.  
My comeback, though gradual, suffused my soul with hope  
That I could move house, go to school, have stamina to cope;  
To Jazzercise, to travel, start a career, make new friends.  
A new person was emerging with a body on the mend.

\*\*\*\*\*

Some years of normal life went by  
Before the dread fatigue came back.  
The virus that I'd thought was gone had once again attacked.  
The passage of a few weeks more served only to confirm  
I was destined to live again in the world of the infirm.

My steps s-l-o-w-e-d. What had been easy now was HARD.  
I had bad days and better days, but had always to be on guard.  
For the signs I'd consumed more energy  
Than I was currently allowed.  
To save myself, I withdrew.  
I avoided every energy-consuming crowd.

I attended no classes. I attended no shows.  
My house seemed to get bigger. I outgrew all my clothes.  
Too weak, too tired for exercise—  
Or other help that I might choose—  
It wasn't long before there was an old woman in my shoes.

I rarely saw my friends, and only then I was 'up'.  
Our visits were confined to tea once we used to sup.  
In time, most drifted away to lives I could not share.  
I really didn't blame them or consider them unfair.

The projects, essays, poems that grew inside my mind  
Remained as dreams, unless completed in a given time  
Before I lost the thread and they became a hazy cloud,  
For time is only really time if energy endowed.  
\*\*\*\*\*

Energy and stamina shape our lives. We accept them as our due.  
Never dreaming how miraculous it is that we can learn and do  
A hundred things a day –  
Make decisions, bathe, clean house and cook,

Hold down a job, take a class or shop,  
and maybe read a book.  
We take for granted, making plans, we expect them to be done.  
We depend on having energy for work as well as fueling fun.  
We drive our cars, call our friends,  
And still have strength to do the dishes  
Without respecting the energy that lets us carry out our wishes.

Sometimes I want to shout it out to people everywhere:  
Be grateful for the precious gift you have, and be aware  
Of your life-giving energy, every day from dawn to dawn,  
And imagine what your life would be if all of it were gone.



## THE GIFTS OF ILLNESS

By Joanna James

“Too bad you’re sick. Get well soon,” the well-intentioned say,  
But inside I find  
I’m disinclined  
To recover, to obey.

While it seems perverse of me to persist with this intention,  
To honor weakness, limitation,  
Even when there is frustration,  
This illness surely has captured my attention.

To live outside the worldly stream, I might have not thought to choose,  
But viewed from here  
It’s becoming clear  
There’s less than supposed to lose.

Unplugged from the clamoring current of ceaseless stimulation,  
My senses live  
More sensitive  
To the birth of a strange elation.

When I could swim life’s turbulent waters, was busy every day,  
What I *did* was all.

I never heard the call  
That said, Just *being* is okay.

I’m now aware of what I missed when I was free to run around,  
To play and do  
And carry through  
Activities that now astound.

I’d missed the meaning of the small, the time it takes to ponder.  
The pace was fast,  
The field was wide,  
But now I’m free to wonder.

Living in the moment was once impossible to do.  
Now I re-examine old beliefs,  
Ungrasp the future with relief.  
I’m grateful to be seeking what is real and what is true.

Cut down and held by illness must seem to some a curse,  
Yet it’s forcing me  
To see differently  
This gift of love from the Universe.

It seems that I have permission to be just who I’m meant to be;  
Though I’m undressed,  
I’m fully blessed,  
A chosen one through alchemy.

And if this illness doesn’t end, and if it means more strife,  
I’ll not complain  
For I maintain  
That what is healing is my life.

