

# Hep C Stories

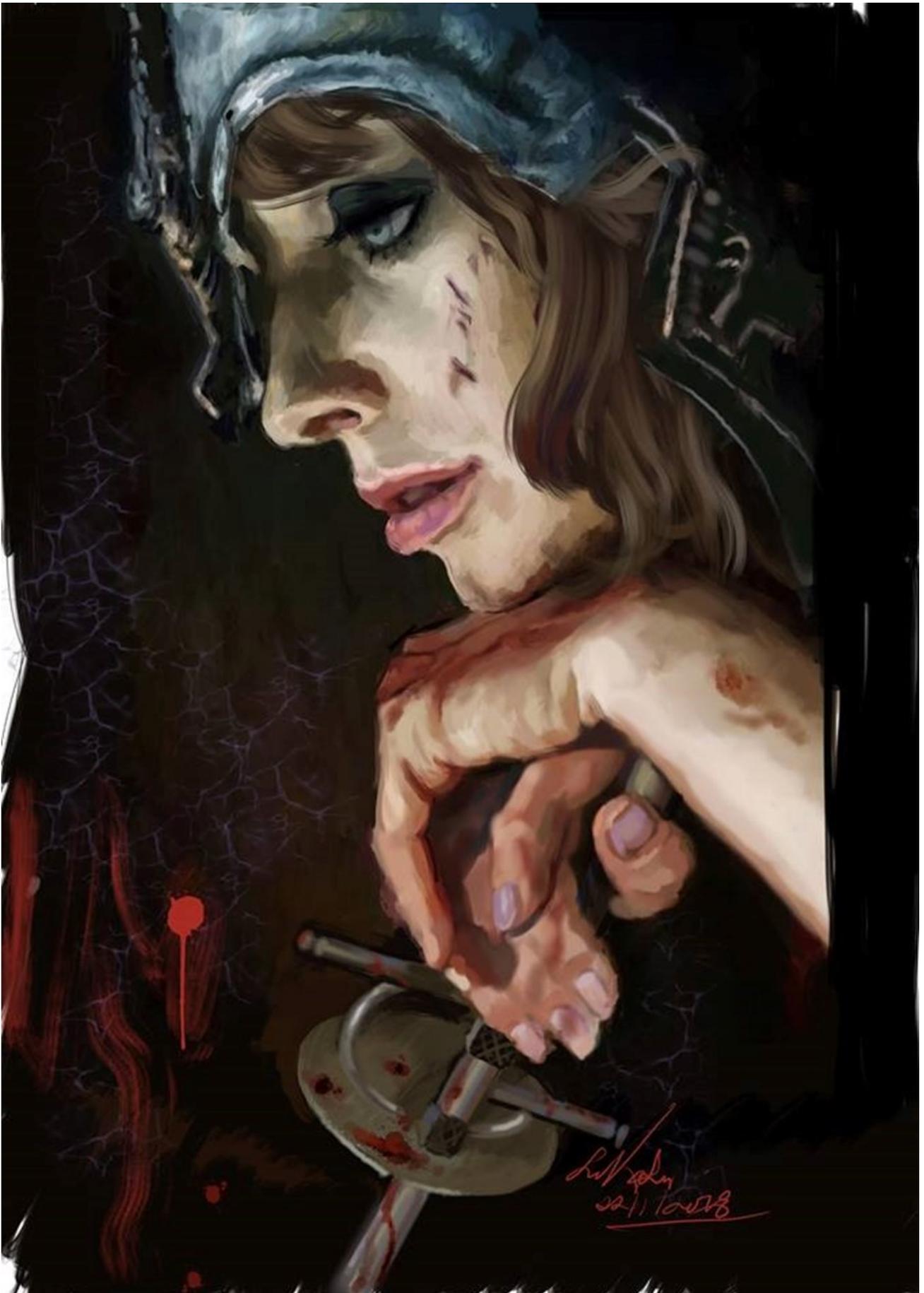
2016-2018



HEP C ACTION  
AOTEAROA

 <https://seedthechange.nz/hepc-action/>

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Painting of Barbara Franks, New Zealand, who was infected with hep C by blood transfusion on the 6/6/66 and was cured with Viekira Pak + oooribavirin in 2016. Dragon Slayed.

By Wellington artist Luka Lu, 2018.

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## **Introduction:**

Hazel Heal, Dunedin, New Zealand.

June 2018.

The original idea for this collection of stories was the theme “I am here to tell you how it feels”. These stories represent all the ways we journey towards ‘slaying our dragon’- be it drug trials, generic importation or state/insurance funded DAA’s.

We are from everywhere; we all travel differently and got here differently. But we all got HCV by accident, we all experience the massive stigma that remains in society, we all get tired, we have all been scared. The online support forums gather tens of thousands of us together in support, kindness, honesty and critically, correct information.

We share stories and memories of those for whom the cures came too late. We hold in our minds and hearts those for whom the cure is there, but out of reach.

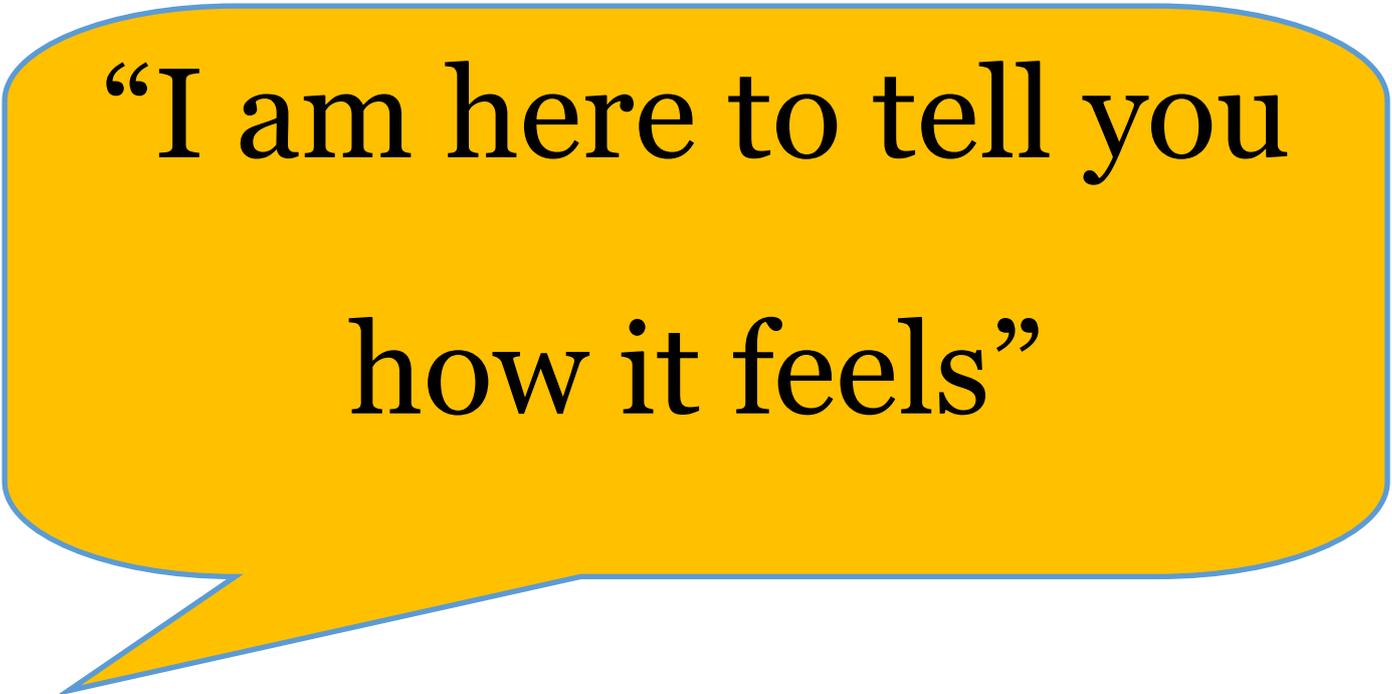
I would like to thank every contributor, not just to this collection but to those forums. I want to especially thank some of our leaders- medical and non medical.

Too many to thank for everything, but special gratitude to daughter Meg Van Hale, for arranging and editing this collection, and the support and art she has given to my journey.



*Regeneration from Cirrhosis*, embroidery on calico

by Meg Van Hale, 2016



“I am here to tell you  
how it feels”

**Adrian R. Mullins, New York State, USA.**

31 January 2016, before treatment.

I don't know where else to turn.

My name is Adrian R. Mullins. I am 33 years old. Anyone who wants to, can check out my Facebook page. I have nothing to hide. I'm a musician and teacher in NYC. I'm drug and alcohol free, I don't smoke, I don't eat sugar and I'm gainfully employed (not for long).

I contracted hepatitis C about 10 years ago; I'm finally at the point where I am extremely sick. I am about 115lbs (from 140)...I'll spare you the details. I can't work, I can't teach, and now, finally, I can't play music. I am starting to get too sick to get out of bed. I have Medicaid-Medicaid that has denied me treatment twice, going on three times. I write this with tears in my eyes. I don't know what else to do, where else to turn. I have a family but they all have insurance and can't figure out why I just don't "go get the medicine." My grandma thinks if you go to the ER some fairy godmother floats down with whatever you need. They triage you, stabilize you, and send you home with appointments that ultimately lead HERE. If I go to the ER they say "yup. You've got hep C. Go to this appointment." And I start the whole process of getting denied again.

I'm at a loss. Soon my next stop is going to be the liquor store and/or a cyanide capsule. AND I don't even drink.

Please. I don't know, this is probably just a fake page for Merck or Pfizer

or something, but if it's not, is there anyone out there that can Please give me some advice? Maybe a NYS resident? Maybe not???

I'm genotype III and have full, active Medicaid. I know, just another piece of shit trying to mooch help from others. But I'll be honest: I'm so scared- I am fading fast and there's nobody to help me. I'm paralyzed from sickness and fear. Please: if there's anyone out there that has some positive words, I'd be more than happy to listen. Cheers all; Fare thee well.

28 May 2018 , after treatment.

Just wanted to check in and say thank you, again, (for those that don't know me or my story); that after being quite sick, that I'm not just surviving but thriving. I'm busy with music, i have a S.O. I truly adore; we have a new home together in NYC and am [feeling] healthier than I ever had as an adult. Again, thanks to the efforts of Greg Jefferys and others, this group saved my life; that's the level of gratitude I have for everyone here and often find myself asking how to reflect these feelings to everyone. Thanks, to everyone here, thanks for your support and keep fighting the good fight.

Cheers, my brothers and sisters

“My next stop is going to be the liquor store and/or a cyanide capsule...I'm paralyzed from **sickness and fear.**”

“After being quite sick, that I'm not just surviving but **thriving.** This group saved my life... keep fighting the good fight.”





## **Rob Crapper, Sakao, Vanuatu.**



1 April 2016

So, six months ago I was getting adjusted to the fact that I was on a downward slide and in all probability wouldn't be around for much longer. It was a melancholy place to be, it had been a terrible year, and my demise seemed to woven into that story, despite the one brilliant solar flare of a family wedding in LA, it had been all downhill, and then a friend (or many) put me onto a lead. There was a Guy in Tassie who had started a kind of Dallas Buyers club to get generics of the wonder drugs that had become available but that you would need to mortgage your house to get hold of.

And I hooked up with Greg Jeffery and his Hepcats.

And what an odyssey the past 6 months have been.

I started with a bang. The immediate effects were manic. Within a few days I felt like I was a teenager in energy, something that had been lacking for years. I was literally bouncing off the walls (there are still bounce marks) we had another wedding to plan and a property that was still recovering from a massive cyclone so it worked out well for a bit. I directed my energies into work. Manic work, and tho I had the energy levels of a 17 year old, I also got the emotional roulette, and the inability to shut down a thought without verbalising it. Unfortunately, rather than being able to see it as an effect of medication it polarised the family and friends around me. Some didn't deal well with me, others were amazingly sympathetic, and although none could understand what I was going through, the FB page Hepatitis C w/o borders was there for me in my darkest times. Here were my peers, here were people going through the same problems and worse.

One of the dangers of feeling 17 in a 58 year old body is the punishment you inflict upon said body, and the harder I worked the more damage I did, awakening old injuries, I popped my good knee re-roofing the house, I did something unspeakable to my collarbone and neck, I trashed my ankles and lower back, and after 3 months of no more than 3 hours sleep a night, it all changed and the long term Ribavirin kicked in and I've been shuffling around in an arthritic daze mentally fogged and

“I was on a downward slide and in all probability wouldn't be around for much longer. It was a melancholy place to be.”

“I hooked up with Greg Jeffery and his Hepcats... The immediate effects were **manic!** The FB page Hepatitis C w/o borders was there for me in my darkest times.”

“Today is my Day of Reckoning. It's been 6 months, and it's a funny feeling... change is in the air. It's just a matter of a few more blood tests, but I'm fairly confident **I've beaten the beast**”

erratic, still pissing people off with uncontrollable verbal tirades, but more forgiving of myself - no choice really, otherwise I'd spend my days in self recrimination, and fuck that. So I tell myself it's the drugs, or my liver, or some such excuse. But, today is my Day of Reckoning. It's been 6 months, and it's a funny feeling. I know I won't change overnight, but after this go-round, I'm not really sure who I'm gonna be when it's all done and dusted.

Either/or change is in the air.

Now it's just a matter of a few more blood tests, but I'm fairly confident I've beaten the beast...

## **Kirsten Werner, Melbourne, Vic, Australia.**

I found out in '92 age 34 that I had this disease that no one knew anything about. Of course I had seen the parades of skeletal people covered in lesions, dying horrible deaths from AIDS. I knew of the little girl in NZ with HIV denied school because of her scary illness. Was this what I was in for??

Shortly after I met Mic. I had to disclose and after an ill-informed GP told him he could be infected by saliva (that's hep b btw) he was off like a shot. I hunted him down so I could at least tell him the Dr was wrong and that he should be tested because he had used iv drugs in the past. I was fairly sure he had it, but not from me so I wanted him tested before the window of transmission from our encounter closed. Sure enough he also was infected.

We are still together and our daughter, born with antibodies but HCV free is 22 this month. I had private health insurance for my " classic " caesarean. I was cut along the bikini line and also up to the navel. Didn't take long for the nurses to read HCV positive on my chart and, even though I could barely move, I was told where the utility cupboard with the mop and bucket was should I drip blood on the floor. My Dr had ordered tablets containing morphine for me which, after a couple of days the nurses started withholding from me "you won't be able to take any of these home you know" (I was and I did). They would give me panadol

"just give it a try". After an hour of agony I asked for my morphine meds which I was denied because I'd already had paracetamol. So there we go....my beautiful private hospital birth experience, extremely physically painful and got to be treated as a dirty drug seeking junkie at the same time. Of course I've had good medical experiences: my dentist, who says he treats everyone the same. But there have been others at pathology labs where you can't help but notice people double glove. My own brother and sister in law (also a nurse) would not let my daughter have a bath with their kids when they were little.

My bloods had always been fairly normal, but I was always sure not to get too far away from my bed. Exhaustion was a constant, my mother thought I was domestically lazy and couldn't understand why I wouldn't get a job. Most of my friends got used to me agreeing to meet for various things and at the last minute stepping out because of the tiredness. I always felt guilty that I couldn't meet others expectations but at the same time my own mother thought I was malingering. My parents sent me to a sleep clinic thinking I must have apnoea, but I didn't.

I had always kept an eye out for the Hep C NSW magazine that was packed with info about new treatments coming. I knew what was involved for type 1a in the first interferon treatment and the likely, poor, outcome. Then came added ribavirin and pegylated interferon but still the outcome seemed unfavourable and my daughter had started high school and I wanted her to have all the support I could give. When she

was midway through secondary school I believe sofosbuvir was being trialled with interferon but my professor of infectious disease sort of talked me out of that one. She said my liver was good (the Fibroscan machine had recently come into use and I'd avoided the dreaded biopsy) and better drugs were coming. Finally, my daughters in final year of secondary school and I start agitating for trials they said were running later that year (perfect timing I think). Well, the trial was always manyana for the next 2 years.

During those 2 years of agitating and frustration with the trial people I turned on a news program and there's Mr Greg Jefferys describing how he went to India and bought his own cure affordable and without fuss. Somehow, I contacted Greg, read his DIY blog, joined the FB group and was ready to roll. No more waiting, as I had been since '92. I ordered sofosbuvir and ledispavir from a compounding pharmacy in Sydney and they were the next lot to keep me waiting with false promises about timeframes. More manyana, more next week. After about a month of this the trial people ring up and announce its happening come into the hospital in 2 days. So I ring the compounding pharmacy who still haven't compounded anything and speak to the girl who finds it amusing how often I've rung her. I tell them to cancel my \$2600.00 order.

I can't believe it. The first time I show up for the trial they give me \$20 and a month's supply of viekira pak and ribavirin which is about the size of a shoe box.

“I found out in '92 age 34 that I had this disease that no one knew anything about.”

“I had private health insurance for my " classic" caesarean...Didn't take long for the nurses to read HCV positive on my chart and, even though I could barely move, I was told where the utility cupboard with the mop and bucket was should I drip blood on the floor.”

“My Dr had ordered tablets containing morphine for me which, after a couple of days the nurses started withholding from me... [I was] treated as a dirty drug seeking junkie.”

“I turned on a news program and there's Mr Greg Jefferys.”

“[My Partner] gets his meds in about 5 days and we take them together at night in a sort of romantic ritual that will give us longer together.”

“This year I'm 60, never thought I'd make it!”

A month later Harvoni comes on the NHS and I've got my partner and our GP and our local pharmacy all lined up and ready to roll. He gets his meds in about 5 days and we take them together at night in a sort of romantic ritual that will give us longer together.

I must confess I had a little cry driving home from the hospital with my precious, precious v pak beside me and I took the first dose with some French champagne (the Dr said I could drink within the guidelines as I have no fibrosis).

Since diagnosis in '92 I had become fairly knowledgeable about HCV. I read everything and even imported a book from the uk before there was anything here to be read by non-gastroenterologists. I have been helped a lot by being a member of a HCV support group that I found through Greg Jefferys. Although my best mates knew of my HCV status, I don't want to bang on to them about it all the time and my mum didn't understand why I had normal liver function but slept all the time. The people in the FB group are there for the purpose of helping each other and helping the freaked out newly diagnosed gives me great satisfaction in particular as I know what it was to have those nightmares when I was 34. This year I'm 60, never thought I'd make it!

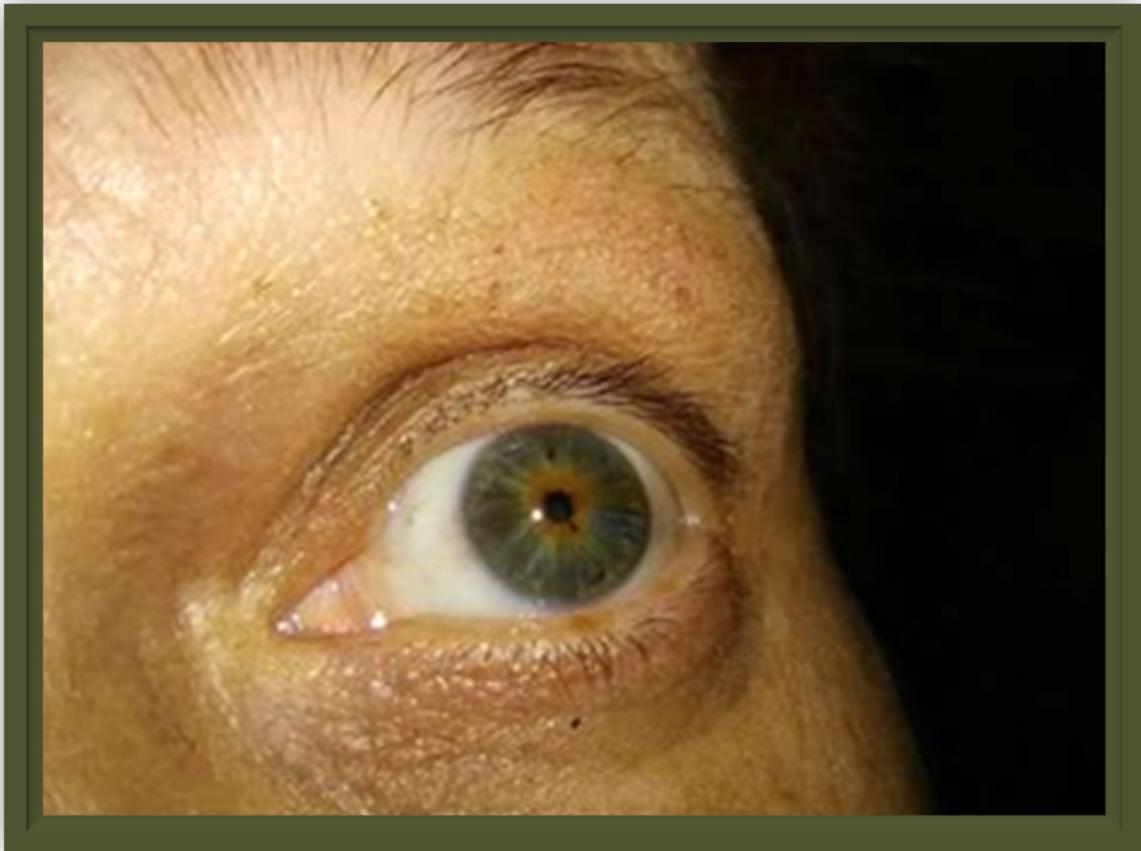


**Lisa Kaye Gray, Louisiana, USA.**

I know most of y'all have seen my eyes, I did 16 weeks tx, undetected at 12 weeks, F4, I can't get over how WHITE my eyes are! I'm telling y'all we stumbled upon the FOUNTAIN OF youth!! 😊😊😊

they used to be so dingy yellow/brown hardly no white, now look, I look at my eyes every time I'm near a mirror I'm really in AWE... ❤️

Thank you Greg Jefferys!!!! Just talked to my Dr, who DID not approve of me doing Generics, she did my labs at 12 weeks, UNDETECTED,



finished my last 4 weeks Sunday March 4th, she said since my labs were ALL GOOD AND IN NORMAL RANGE ANDDD UNDETECTED on January 29th, NO LABS TIL September to ensure SVR 24, one happy old

hippy grandma here! Ha, and to think she SCREAMED AT ME NO DONT DO GENERICS!!!! I feel 100%.

I'm 13 days Post treatment, I've had Hep c for 25 years with F3&F4, I feel GREAT LIKE A NEW PERSON!! I'd rather die trying to cure myself then die of the virus an complications that goes along with. At least I know I'm undetected right now after 16 weeks of treatment, i kicked that dragons ass, now just waiting till Sept to show SVR24, I KNOW IT WILL!

“We stumbled on the **fountain of youth!!**... One happy old hippy grandma here!”

“I've never had HepC yet it consumes my life, this virus took my Carla, my beautiful Irish wife”

“I will see this virus **eradicated.**”

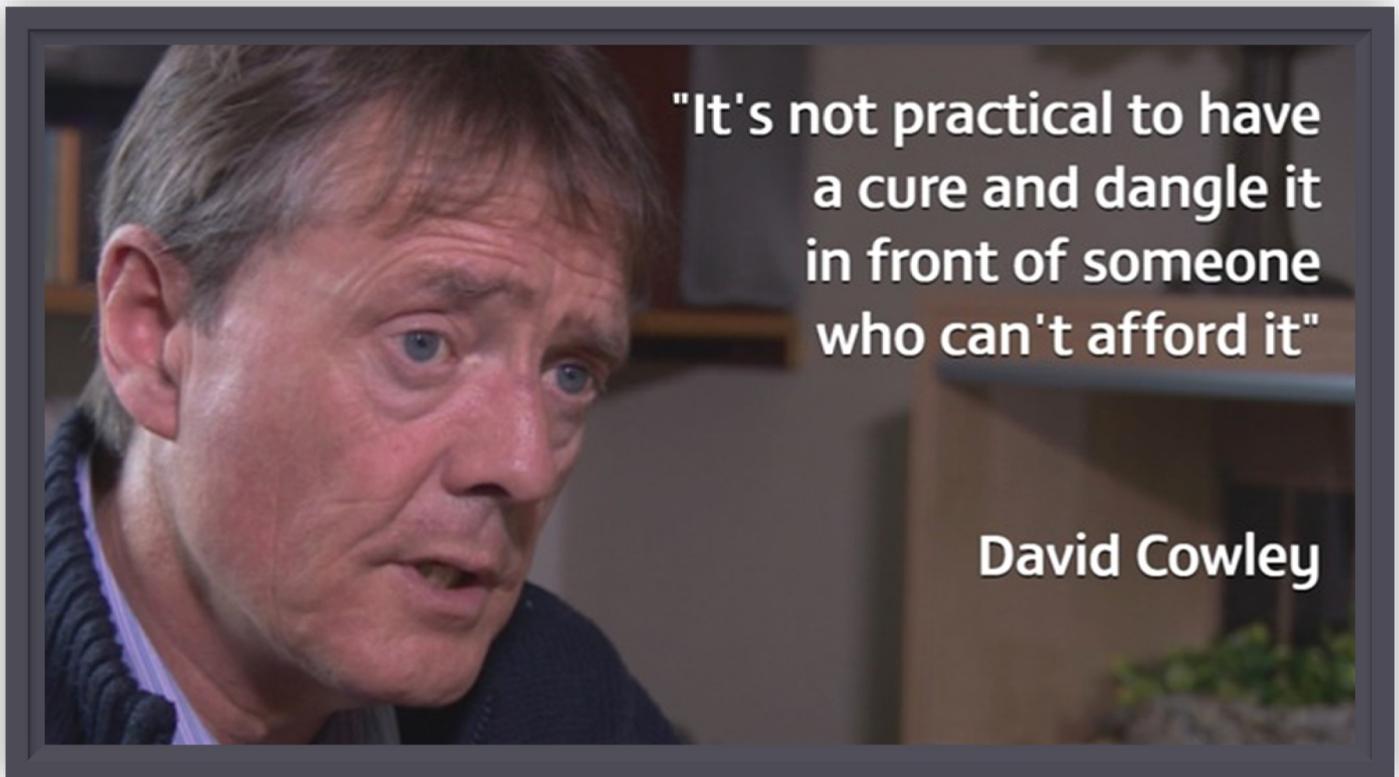
### **Bob Goode**

My name is Bob Goode, I'm one of many HepC left behind to founder in the grief. I've never had HepC yet it consumes my life, this virus took my Carla, my beautiful Irish wife December 28th 2008 after an 8 year fight. There were no safe effective treatments back then, not like we have now. I took care of my Carla till her last breath kissed my cheek. All I wanted was to follow her. There are many like me around the world and like me many have found their way out of the darkness by joining support groups telling the newly diagnosed their lives are not over, to never give up. This is my life now, my whole reason for being. I will see this virus eradicated.

## David Cowley

(reprinted from below, excerpt, Credit ITV)

<http://www.itv.com/news/wales/2016-06-22/this-man-set-up-a-buyers-club-for-people-to-access-cheap-medication/>



This is a story about how patients can access new drugs and about the amount they cost.

David Cowley doesn't like to be compared to the Dallas Buyers Club, the group which smuggled unlicensed medicines into the US for HIV patients in the 1980s.

However, comparisons are inevitable.

But this isn't the 1980s, he isn't smuggling drugs and it's not about HIV.

He calls himself a 'facilitator' between patients all over the world who need access to a potentially life saving drug for Hepatitis C and the Indian drugs companies who creates it, or at least a version of it.

Just like a travel agent, he is the middle man.

The drug is called Harvoni. It's been approved for use on NHS patients with the most, they get access to it first, meaning others are having to wait.

It costs the NHS £35,000 for a 12-week course, but a generic drug produced in India costs only \$1,000 because a patent has not been granted. So people from all over the world are contacting David asking for help.

David, who took the drug himself, says he's helped people from countries including America, Brazil and France. They usually find him though Facebook.

This is all perfectly legal because a loophole means medical drugs can be imported for personal use.

He says he insists people speak to their doctor before getting any medication but medical experts have advised patients to be cautious.

## **Glen Needs**

Survives: with liver transplant, love and hope.

It's my birthday, well it's my other birthday, you see three years ago on the 5/05/2015 I received the most wonderful gift of life a new liver from a dear soul whom I have no knowledge of whatsoever, male, female, young, old, I don't know I've never received any information about them at all.

I have the option of writing to the family to thank them for their incredible gift but until now I haven't felt led to contact them but I'm quite open to do so at some point.

At present it seems today's birthday has more meaning to me than my actual birthday, heck the only reason I remember my actual birthday is if my girls remind me.

So today I'm so reminded of you all who took the time to pray and care for my family and myself.

Now I've wrestled with whether or not I should post what I'm about to post for quite some time, that is sometime ago I wrote a few words about our experience and it's very personal but written with those in mind who are going through and of course one day we will all go through similar experiences.

So I trust you will be encouraged if not be silent.

I regularly receive many people's kind concerns and queries, so here is a

little update.

I just wanted to share with you a snippet of my life, a testimony of God's grace these past (almost) two years now. It's somewhat a 'coming out of the closet', so to speak. This is only in the hope of encouraging someone to hang on, to be faithful, and never give up on hope.

So, here we go.

I have been living with Genotype 1;A Hepatitis C, and feeling the shame, embarrassment and consequences of it since the late 1970s, although I had no idea there was anything wrong with me till much later down the track.

From here on I don't mean to be negative, but this is my story, so be patient and hang in till the amazing ending.

I met the most beautiful girl I'd ever laid eyes on back in 1982, and we were married within the next year in 1983. All through the '80s I just didn't feel quite right. There was something going on with my health and the doctors didn't have a clue what.

It wasn't until around 1990, the year my daughter Clara was born, they finally came up with a name for the illness. They didn't seem too concerned, so life went on as usual. Around 1992 my doctor recommended a liver biopsy be done. It was at this time I became aware of the seriousness of the disease. So when the results of the biopsy came back the diagnosis was Cirrhosis of the Liver. I was told at that time that I might possi-

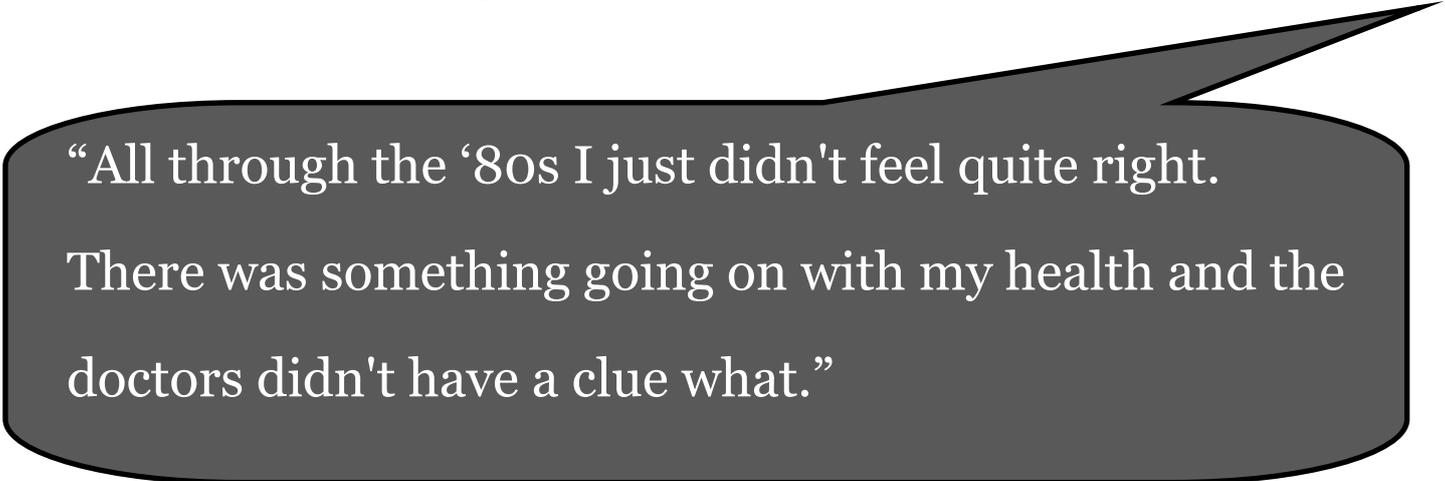
bly go on indefinitely without too many problems, so that's what we did. We just got on with our lives. Two years later my son Kevin was born.

About 1996, another shock - I was told I had liver cancer and needed to have the left lobe of my liver removed.

This was a crushing time for us as a young family with two children aged 6 and 2.

I agreed to go ahead with the procedure.

Eight hours of surgery later I had had half of my liver removed, only to be told they had found no trace of cancer at all! It was a long and difficult 12 month recovery period for me to regain my health.



“All through the ‘80s I just didn't feel quite right. There was something going on with my health and the doctors didn't have a clue what.”

This was an especially difficult and heart-breaking time for Diane as she had our two young children to look after, and in the midst of all this, she lost her father whilst I was in hospital and attended his funeral without me by her side.

The next 22 years would lead to many more diagnoses of liver cancer,

which all turned out to be false alarms after further tests. These false alarms took a great toll mentally on me and my family. It was like waiting for the diagnosis that was going to be the real thing.

“About 1996, another shock - I was told I had liver cancer and needed to have the left lobe of my liver removed. This was a **crushing** time for us as a young family”

There is so much detail of this journey and the people we've been involved with over the years, and the encouragement that we both received and what we've encountered, but I will just skip over to spare you all the details. Perhaps I will write in more detail at some point just to have a record, but not now.

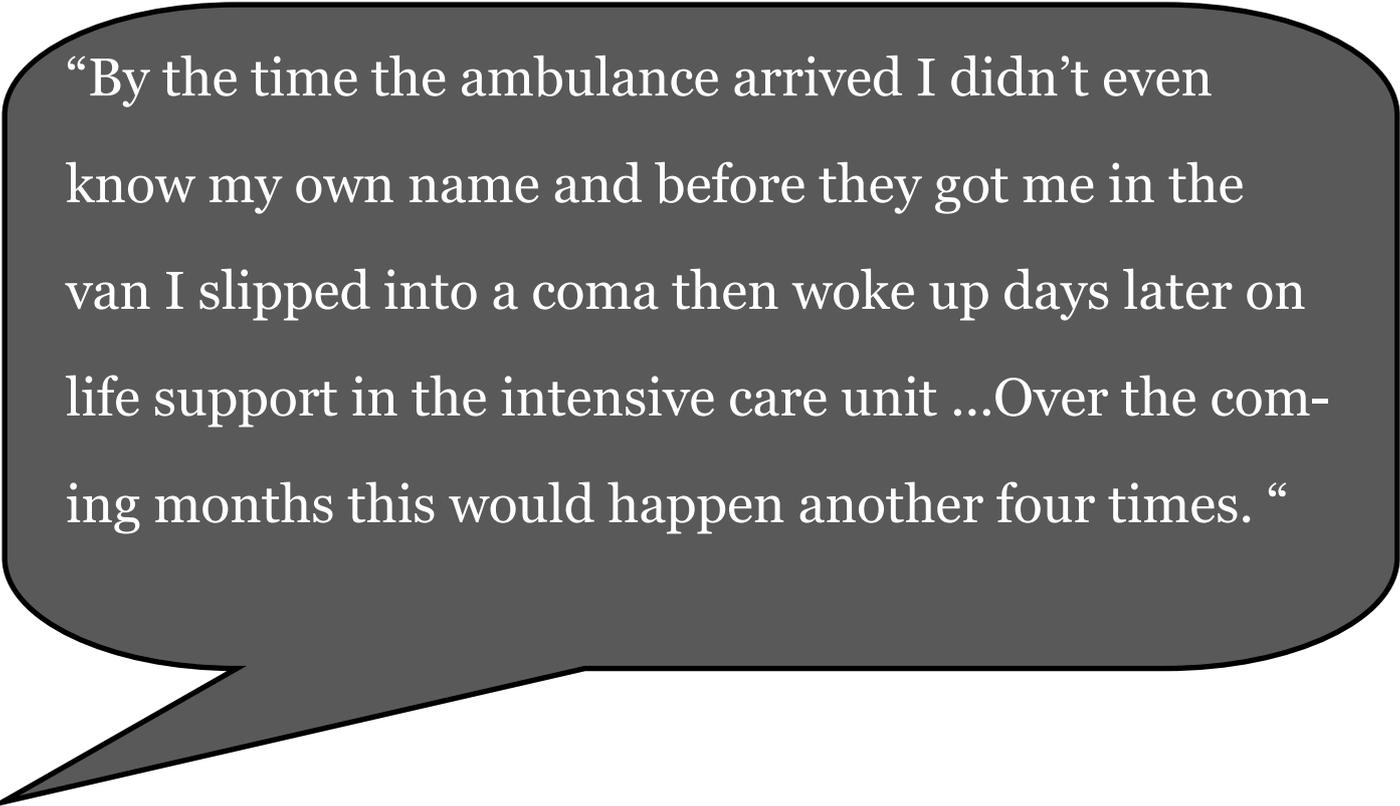
My health started to progressively go downhill in 2014. I became forgetful and lethargic, I kept telling myself “I'm just getting old”, but as the year went on it became apparent it was way more than age affecting me.

It all came to a head in early December 2014 when my wife said she's ringing the ambulance after noticing my mind wandering, I argued and protested at the thought of wasting the ambulance time but she wouldn't have it, and dialled 000.

Well by the time the ambulance arrived I didn't even know my own name and before they got me in the van I slipped into a coma then woke up days later on life support in the intensive care unit at the PA hospital with encephalopathy.

Over the coming months this would happen another four times. Encephalopathy is caused by liver failure. When the liver gets so sick it can't get rid of the poisons in your system, the poisons then affect your brain.

Well, in the next months, things got progressively worse as I was in and out of ICU and Ward 4E at the PA hospital, with lots of various complications related to liver failure. For example: oesophageal varices, which is akin to having haemorrhoids in the stomach. On several occasions these had burst, and as a result I vomited massive amounts of blood - on one occasion one and a half litres.



“By the time the ambulance arrived I didn't even know my own name and before they got me in the van I slipped into a coma then woke up days later on life support in the intensive care unit ...Over the coming months this would happen another four times. “

Ascities (which is fluid on the stomach) meant they had to drain my stomach of fluid by sticking a needle in my abdomen, which felt like a bic ball point pen being shoved in. One day, getting closer to transplant, they drained off 16 litres.

My weight plummeted from 75kg down to 45kg. I was nothing more than a skeleton with a big belly.

By early April 2015 the doctors put me on to the liver transplant waiting list, where I teetered between life and death for the next month. By God's grace I somehow managed a stable period so they sent me home to wait on a new liver. I had been home for some days, still extremely sick, when I developed a blood clot in the portal vein. They put me on drugs to try to clear the clot, because if the portal vein is blocked they aren't able to transplant. Because the portal vein is what connects the liver to your body, not having a good portal vein meant no new liver!

These were very difficult days for all of us. My family were helpless, watching me fade away with each passing day. Up to this point my prayers were to the effect of "Lord, heal me or take me home!" The pain and suffering and watching my family go through this nightmare, and trying everything to encourage me was just more than I could bear.

About that time, leading up to the transplant, I felt all my selfishness come erupting to the surface as I completely broke before God realising my prayers were no more than me demanding of the Lord what I wanted Him to do for me, rather than giving Him rightful place to do as He<sup>33</sup>

pleases.

In my brokenness my tears of pain turned to tears of love for my Lord as I realised His forgiveness and loving kindness. My prayer now at this point was a willingness to accept whatever His plan was for me, whether it was to go on in great suffering, or for Him to take me home. Whatever the outcome, it was going to be for HIS will and glory, not mine.

It's truly amazing how God works! In that very hour as I lent before Him in complete surrender, there came the call from the hospital.

“We have a liver for you! Please come in!”

Well, my wife and kids were so excited they could hardly think about what they needed to do to get me there!

It all then hinged on this clot in the portal vein. The transplant surgeon spoke very directly and said it wasn't the best situation to be in. The surgeon then ordered a scan to be done, after which we would have an hour or two to wait for the decision from the doctor on whether or not to proceed with the surgery.

This hour seemed to go on forever. Until this time, my daughter had been a tower of faith and strength, but then she just broke down and cried. The load she had been asked to carry was just all too much for her as she realised I may not get my new liver.

Well, the Lord was so present with us, my confidence in him welled up as I assured my family all was going to be well no matter what, but even

while saying this we all knew there wasn't much time left. It HAD to be this day.

The surgeon then came and told us there was some flow! He wasn't sure if there was enough but he decided to go ahead and do his best.

At this point I said, "If things don't go right I don't want any intervention to keep me alive."

He promptly turned to me and said, "I'm going to get you through this! I'm not doing this operation to fail. We WILL succeed!"

On hearing these words all our confidence soared.

The procedure was far from straight forward or as the doctor said; It was a rather tricky procedure, I received 42 units of blood as I bled terribly.

I was put into recovery after 8 hours of surgery. There I lay for some hours, critically ill. Even my wife wasn't allowed in while they continued their care. I was then put into intensive care where I woke two days later. I stayed in ICU for five days and was then transferred to the ward.

Well, what a journey I've had since then! One of my greatest joys was being told I could eat whatever I like, so two days after I got to the ward I asked for a vegemite sandwich - and it was heavenly! LOL!

I had to learn how to walk again after being bed-ridden for months, so they got me out of bed on day two at the ward. What a sight I was! Black and blue everywhere, lines and drains all over the place, and nothing but skin and bones.

But slowly, slowly, I started to make some progress. One of the first things I noticed was when, being assisted with bathing, I looked in a mirror and saw my eyes were no longer bloodshot and the colour had returned. It certainly gave me the courage to keep pressing on.

The next weeks in hospital were very challenging as they pumped me full of a cocktail of various drugs that had different effects on me both emotionally and physically.

Two weeks after transplant I was out of hospital and staying nearby at Diane's mum's unit, as I still had to come in daily for 'bloods'.

Another two weeks, and I finally came home, where my recovery still continues to this day. Some eight months after my transplant I went back to work, and shortly after, bought myself a motorcycle. Wow!

Through all this my wife, my son and my daughter have been nothing short of heroic in their incredible efforts to always be there, to encourage and give me the love and strength to face each passing day, especially as I grew steadily sicker. They did literally everything for me, including bathing and staying awake sometimes for days on end as I struggled for life. I simply cannot emphasise enough the pain they were enduring through this whole experience.

I sit here in tears thinking of one dark day I was feeling quite defeated when my daughter grabbed both my cheeks and with tears welled up and rolling down her beautiful face, cried into my face, saying "Don't you dare give up! I need you! Don't you dare give up!"

Well! What's a man do when faced with that? We cried together, and I cried out to God through terrible pain for strength of heart to endure whatever came.

And the Lord! He answered that prayer! It was a prayer of complete surrender to His will in that moment, as the tears fell down my face in the realisation of my weakness and utter dependence on Him. I just asked Him to forgive my selfishness and said, "I'm ready to go Home, or to go through whatever lies ahead".

I will never really understand, this side of Heaven, the terrible things we must endure at times, but one thing I do know - He will never leave us nor forsake us. He told us He would take us through and never leave us stranded.

It's so paramount that we keep an eternal perspective. I most certainly believe in the healing power of our Lord, but I've come to understand it's the exception, not the rule, because one day soon we will ALL be healed completely, and by His grace hopefully soon.

I must mention here that there were so many people supporting us in so many different ways, some from a distance with prayer and some absolutely 'hands on'. There were a number of very special people who stepped up and selflessly gave their support in practical ways, such as visiting me regularly in hospital. Because I was so sick I said I didn't want visitors, but they came anyway, and I can't tell you how much this meant to me. There were those who mowed my lawn, and there were those who

made sure Diane, Clara and Kev were okay.

This I write with tears as I think of those who came to intensive care and tenderly and lovingly supported me as I fought for my life. They were the faces I saw the numerous times when I awoke from a coma, still on life support and not able to communicate. Then there were those that I only know were there because my family told me so at a later date.

How do I ever say thank you? I just don't know.

I've since been through the new cure for the Hep C virus now, and it's working wonderfully! My liver function tests are all normal for the first time since I can remember.

Ps.

My family are completely disease-free. It's almost an impossibility to catch Hepatitis C from anyone, but understandably people get quite paranoid about these things until they do a little homework and educate themselves. So for me to come out and reveal this is difficult, but there is a wonderful hope just around the corner for me and many thousands like me.

You may be aware that the government has recently agreed to subsidise a new cure for Hepatitis C which has a 98% success rate. It is an answer to prayer!

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## NOW ON TO - CHAPTER TWO

I wrote all of the above some months ago wondering when would be the appropriate time to share.

WELL, TODAY IS THE DAY!!!!

This day, the 11th January 2017, after some 46 years carrying the cursed Hepatitis C virus, I received the most wonderful news.

I AM CURED! NO VIRUS! UNDETECTED! GONE!

When the doctor gave me this news today I broke down crying in his office as the news sank in to the very depths of my soul, and memories flashed before me of all the years of the pain, the embarrassment and shame, the pain of rejection of my friendship by people and family I loved and let in enough to share my secret, only to hear “Please stay away from my kids, we prefer you don't come around anymore”, or the ones that would just make no more effort for friendship, as once they found out they became evasive and gave me subtle messages of “Sorry, we just can't take a chance with you”.

And of course then, there were the friends who DID take a chance with me, the ones I have been sharing my life with, and with whom I have<sup>38</sup> de-

veloped wonderful life-long friendships, the ones that accepted and stuck by me, the dear ones that said goodbye to me as I lay dying in a coma, the ones that shared communion with me in intensive care.

How on earth do I say thank you? I just don't know.

This is the most wonderful day

I praise God for His wonderful blessings, and pray God bless you all.

Love Glen.

“By early April 2015 the doctors put me on to the liver transplant waiting list, where I teetered between life and death for the next month. “

“I was put into recovery after 8 hours of surgery. There I lay for some hours, critically ill. Even my wife wasn't allowed in while they continued their care.”

“Memories flashed before me of all the years of the pain, the embarrassment and shame, the pain of rejection of my friendship by people and family”

“We have a liver for you! Please come in!”

“Some eight months after my transplant I went back to work, and shortly after, bought myself a motorcycle. Wow!”

“Through all this my wife, my son and my daughter have been nothing short of **heroic** in their incredible efforts to always be there”

## Pilot McBride, Australia

If one does not get out of bed one will miss the greatest show on Earth, sunrise, the dawning of new hope, new surprises, new learning.....

3 April 2016

Hello group members,

I am new to this group, I am a 61 year old who was an idiot during the 70s and ended up with HCV. I was pretty crook in the late 80s then received the bad news in 1992. Since then I have led a pretty sober lifestyle, but was ridiculed and alienated by my work colleagues and employer and was sacked 2000 (when I told them).

I participated in the interferon/riboviran(?) treatment in the early 2000s which resulted in all but 2 of my previously good teeth falling out.

Every day brings new thought, new excitement, new experience, some not so good, but an experience. I felt I needed to fight and fight hard to protect my family, to ensure that they were respected for who they are and not disrespected for who I am and for what I did 30 years earlier.

This abuse I might add was led by our local (and only) Doctors' Surgery

in town, I live in country NSW and I know for a fact that at least 30 HCV sufferers, me included, were banned from the surgery by the senior partners. The only sufferers they'd treat were those from the local gaol, and only because "they were contracted to do so".

Today I await my calling to start treatment in a nearby major town, I do so with joy and no apprehension, I made it through the interferon fiasco, have been shot, kicked, and had bones broken. I fear failure of my character, I fear failure of the treatment, but I will never fear having a go.

VC is currently at tad over 8mill and, well you all know the physical failures our bodies go through, but I can still hold my head high amongst my true friends, limited in number now, and I still volunteer for community projects and for local businesses who need help. Sometimes I give my mates the sh#ts for continuing with a project until collapse, but there is nothing more insulting than failure to complete.....

As many have said in the posts I've read that starting the day is very hard. At 61, yes quite hard, but if one does not get out of bed one will miss the greatest show on Earth, sunrise, the dawning of new hope, new surprises, new learning..... One will miss so much..... There is much to contend with, but I know in my heart that there are those amongst us who are worse off than I.

To all sufferers of this insidious disease I pledge my unwavering support, my assistance in any way possible, and my ear, my shoulder, I'll even double as a punching bag if needed. I most solemnly promise that I<sup>4</sup>will

support you in any way I can, to listen to you, to be with you if necessary, to hold your hand, to protect you. I promise you your privacy.

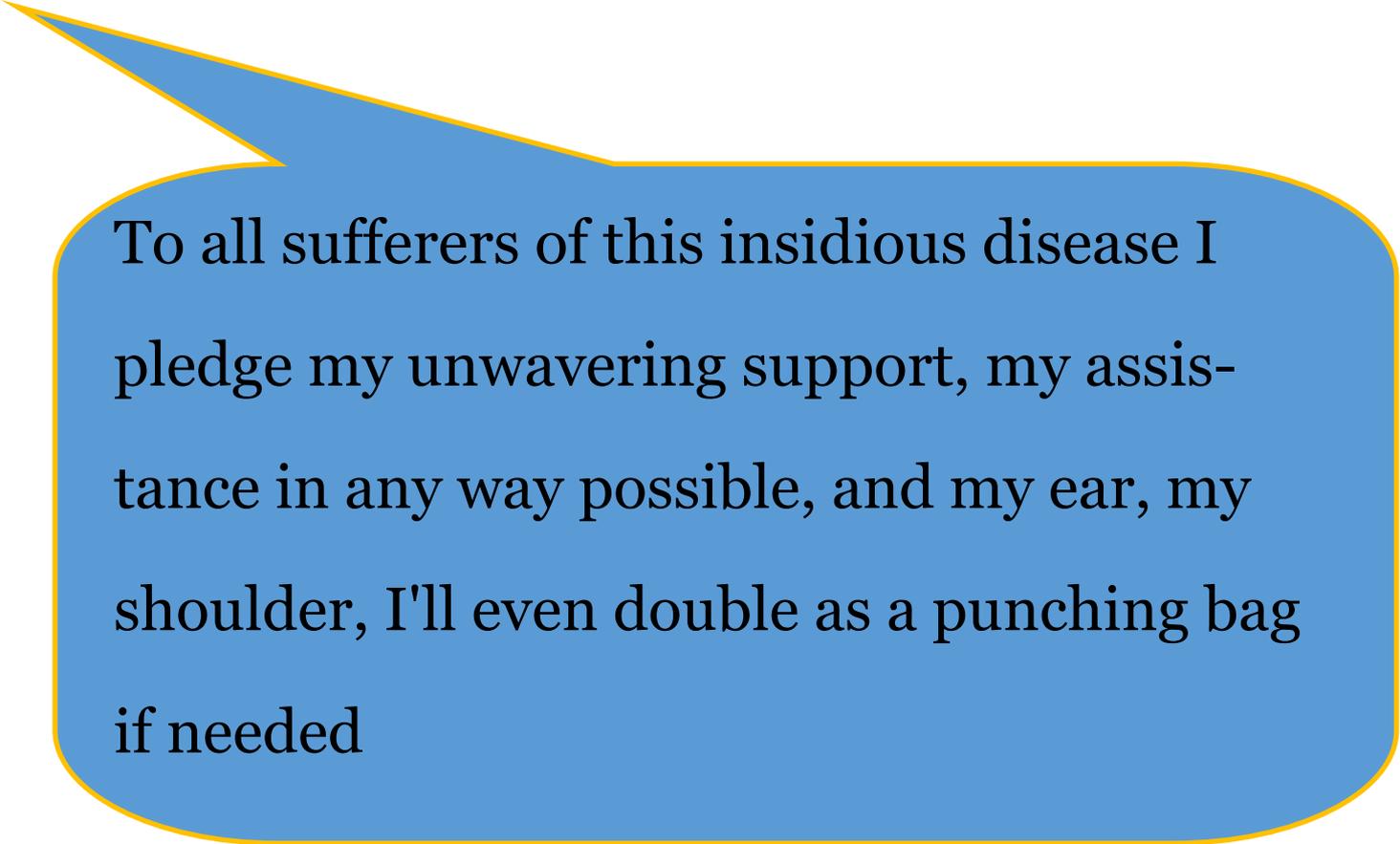
"When the going gets tough, the tough get going."

I wish you all my most sincere best wishes.....

And then, 6 weeks later, after transferring to GP2U Telehealth:

Please excuse me while this ol' fart has an emotional breakdown. Just got off the phone with Dr. It shocked me a bit that he would ring me, but the news was good. UNDETECTED. From over 7mill to zero after 4 weeks.

**Stone the bloody crows!!!**



To all sufferers of this insidious disease I pledge my unwavering support, my assistance in any way possible, and my ear, my shoulder, I'll even double as a punching bag if needed



## **Dale Valiukas**

I started treatment in 2015, just before I got married hoping for a better quality of life. I completed an eight-week course on Harvoni in March of 2015 and am still to this date undetected. I had stage 2 fibrosis and a fatty liver which have since improved and I totally eliminated my fatty liver through diet and exercise and many of my health problems are alleviated. If anybody has a chance to cure their virus, don't wait, give your liver a chance to heal and start living a better quality of life!

Respect & Regards,

Dale.

## **Angela, UK.**

From the tone of the visa doctor, who phoned up, I understood that hep C was a very serious condition, but if treated early the outcome could be good and so that was it. I wouldn't be joining my husband in a Middle Eastern country, the suitcases would remain on the bed and I would not be on the plane. There was the test for active chronic hepatitis C to be done. The only way that was going to happen fast and try and sort this situation was to go to a walk-in-clinic blood testing clinic in London. Reading it up the chances were 75% that I'd be a positive and yes it did explain the falling asleep on the bus all the time and other minor symptoms. Yep, it came through positive

I'd said goodbye to people and they'd wished me well in my new life and now I had to admit I'd got a stigma disease and yet I'd never used recreational drugs or had a blood transfusion. I'd lost what I'd had and I'd lost my future. The reception I got from the local surgery was nothing like when I had breast cancer. There was nobody going to run races for research, no badges, no bucket collections, no strawberry teas, or fund raising dinners. This was it. My husband was off abroad and I'd lost everything. I sat in St. Martin in the Fields Church by Trafalgar Square in London tired and crying.

Having had cancer I read the NHS Treatment Guidelines and understood that as early stage (no going yellow skin, no swelling abdomen and

discovered by a routine test) I was going to be allowed to become an invalid before I was ever treated and then when bad enough the NHS would try to row me back to health. It was barbaric and all because the treatment for a few tablets was going to cost thousands.

It wasn't very long before I discovered I could quite easily access generic medicine legally through a reputable organisation, be cured and start my life again. Next week I go for my 12 week test and hopefully it will be my third hep c undetected result.

This story will have a happy ending, but I am still angry at being medical collateral between pharma companies and the health service. I think I will remain suspicious of the authorities for the rest of my life.

“I had to admit I'd got a **stigma disease**....I'd lost what I'd had and I'd lost my future.”

“Next week I go for my 12 week test and hopefully it will be my third hep c undetected result....This story will have a **happy ending**.”

## **Carolyn Brackett, USA**

I have had hepatitis C since 1988 when I had a blood transfusion. I had no problems until about the last five years. I started noticing increased fatigue, forgetfulness, memory problems. I became bedridden for 6 months and then I found a link FixHepC that talked about generic medication. I was offered Interferon and Ribavarin years ago but did not want it but my symptoms weren't that bad back then either. When I found FixHepC on Facebook I thought it was too good to be true. I am retired and could no longer work. I no longer had insurance.

I tried writing to Gilead but did not get far as the doctor said he would only follow up with me if I was seen twice weekly. I could not afford that so that was out. I made my appointment with Dr. James Freeman at GP2U, sent him all my labs and got a prescription through FixHepC. I also got some extra from Greg Jefferys, as I am genotype 3a, a more difficult to cure genotype. The first month I felt like I was having panic like feelings. By end of second month was able to stay awake and go outside and work. My brain fog had lifted significantly. By 4th month was even better.

I did not have a doctor follow me but always got my lab and they were all within normal limits. I am now 6 months posttreatment and cured! I had nobody I could talk to about my disease or anyone who understand why I was so tired and basically out of it. The hep C forums I had joined

helped me significantly. I was no longer alone by myself. There were others who had gone through the same things and felt the same way. The support was incredible from various groups. I cannot imagine going through treatment and having no support. I no longer felt all alone and had other people who understood. Now I want to be supportive of other people because I know what it is like to feel alone. We need easier access to generic medications, make it affordable and easy to get treated. I am from the U.S. and it is a sham the way people are treated who need help, are sick, dying, need a transplant or have already died from this terrible disease.

“The hep C forums I had joined helped me significantly. I was no longer alone, by myself. “

“We need easier access to generic medications, make it affordable and easy to get treated. “

## Janice Retro

<https://janiceretro.wordpress.com/2018/03/02/more-updates/>

“I’m just bypassing big pharma. I’m getting the same medicine at a 0.9% cost!”

I’m still not up to par but I know I need to update this, I’m supposed to be resting for the weekend but wanted to get this done.

I started a liver cleanse 3 weeks ago with drops of UnDa, numbers 13, 20, 48 and 243. They are made in Belgium, I took 5 drops of each, 3 times a day and I’m done now. I’m waiting on more referrals to her so we can keep going. I did get a nosebleed after a week, and I called her to see if this could be caused by the drops. She said no and talked me through it, I was pretty freaked out with my blood going drip drip drip into the waste basket. She told me how to make it stop and if it didn’t after 20 minutes, to call 911. I got it taken care of, it stopped and all was well.

Wednesday night it happened again. I had just watched a season finale and there was some hugging, an ‘awww..’ moment so of course I got all teary and my nose ran. I blew my nose and son of a gun if I didn’t pop a vein. From the last one, I knew what to do and after about 15 to 20 minutes it stopped. I would blot to make sure it was gone, then it opened

up again. This went on 2 more times and after 3 1\2 hours I went downstairs and told the kids I was going to have to call for help. My daughter in law called her mom and her mom said take me to the ER. I was feeling weak and dizzy by then, I have low blood volume and when they take vials to test, I can feel it.

The doctor was really nice and told me how to treat it, and I brought home the plastic nose pincher thing and thanked them for the body art. We think it's due to the dry air in the house and also the fireplace makes it dry too.

Next news is I went to my original liver doctor to make sure that Harvoni is the best medicine for my Hep C. While typing this, I just got the receipt, I have a medicine doner, God bless her! So now I wait for about a week or so and I start a 3 month cure! I need to get rid of the Hep C to stop the scar tissue which is a nice nursery bed for cancer. This man went to India where Gilead is located, one of the 3 countries that makes it, Egypt and Bangladesh are the other two. It's the direct medicine, I'm just bypassing big pharma. I'm getting the same medicine at a 0.9% cost! I had help with the math but that sounds about right.

A few months ago I ran out of RSO, then got some more but have to start back up again. I tried a couple of times, very low dose, but got 'high' and I didn't like the way it made me feel. I thought since I was taking the liver cleanse I'd wait and now with the Harvoni, I'm going to check for interactions in one of the groups that deals with RSO, CBD oils and other mari-

juana cures.

I'm still taking the Essiac tea, I'll probably take it the rest of my life because I love it so much and it does great stuff for me. That reminds me, when I was at the naturopath, we were talking about the tea and I found out that Rene Cassie came to Oregon for some of her herbs. Cool, I like local natural anyway. She told me that when you first start taking it, and I'll paraphrase her words of my own, well the tea is like a magnet that draws the little cancers to the bigger ones and then it starts to kill them. I think that might be why my numbers were higher, I'd been drinking it only a month or two.

That's about all for now, I'm still using the comfrey salve, Owie Be Gone that my friend makes. I need to put some on, sitting here is making it sore so it's time to lay back down, make new blood and rest. It's so good to be rid of the insomnia, I didn't realize how much it's terrible until it was gone.

I'll update after I am on the Harvoni. Some people say they feel better after just a week and the only side effects are a headache but most have no symptoms at all. I'm so excited to get this virus out of my body that's been there since the 80's before it was discovered or tested for.



## Tasmanian Angel Leads Hep C Sufferers to Affordable Meds

POSTED BY DORRI ON JULY 15, 2016 IN ADDICTION, NEWS, OLDS NEWS, WRITING BLOG | 183 VIEWS

Written for The Fix

Australian Greg Jefferys was near death eight months ago. The exorbitant cost of HCV treatment set him on a sojourn to find generic pills. Now he is cured and saving lives.

Dashing outdoorsman Greg Jefferys, 62, delights in kayaking, fishing, rock fossicking and spending time with his family in Tasmania, Australia.

But one year ago, he was close to death. *The Fix's* Dorri Olds caught up with Jefferys via Skype to learn about this man's odyssey.

“When I first started helping people to access affordable hep C medicines,” said Jefferys, “I never thought it would become a full-time occupation. But it has. I don’t want to profit from people’s sickness, though. There is enough of that going on already.”

**“I was rapidly approaching cirrhosis and my doctors said I might have liver cancer,” said Jefferys. Like millions of people worldwide, his liver was being destroyed by the hepatitis C virus (HCV).**

As is typical of HCV victims, Jefferys had no idea he’d had it since the mid-70s. In August 2014 he was diagnosed and told he had contracted it when shooting drugs.

“I left home at 16,” he told me, “and was happy in a kind of crazy way. I was a mixed-up kid living on the streets and couch surfing. I drifted from the hippie culture into the drug culture and became a casual heroin user for a year. Then, for the next year, I became seriously addicted but I quit cold turkey after seeing a few friends OD.”

HCV is a global epidemic. An estimated 200 million people across the

globe have the disease—that's 3.3% of the population—including 3 to 5 million in the U.S., many of whom don't know they have it. Seventy-five percent of those with HCV infection in the United States were born between 1945 and 1965. The largest group are those that shared needles when they shot drugs. Statistically, as many people are infected with HCV as are with HIV, the virus that causes AIDS. Without large-scale efforts to contain the spread of HCV and treat infected populations, the death rate from HCV will surpass that of AIDS by the end of this century and will only get worse.

For every 100 people infected with HCV, without treatment 75 to 85 will develop chronic infection, 60 to 70 will develop chronic liver disease, 5 to 20 will develop cirrhosis, and 1 to 5 will die of cirrhosis or liver cancer. HCV is also the most common reason for liver transplants.

Gilead Sciences, known best for its HIV/AIDS treatments, is now the leader in HCV drugs—Sovaldi (sofosbuvir) and Harvoni (ledipasvir and sofosbuvir)—which can cure nearly all patients within 2 to 3 months. The obstacle is the grossly inflated price tag. Sovaldi costs \$1,000 per pill and Harvoni costs \$1,125 per pill. According to the *Wall Street Journal*, the sales total for Harvoni and Sovaldi reached \$19.14 billion in 2015. For comparison's sake, it took Pfizer's blockbuster medicine Lipitor nine years before it reached its record-breaking sales of \$12.9 billion.

When Jefferys was diagnosed in August 2014, he knew he could never afford the drugs he needed to cure his HCV. Three months of pills would've cost him close to USD\$100,000. That's when he began an exhaustive Internet search for an alternative. He finally found it in India,

where the generic Indian Harvoni for the full 12-week treatment cost the equivalent of USD\$1,350—only slightly more than the cost of one single pill here in America.

Jefferys said, “Gilead has licensed four major Indian pharmaceutical manufacturers to make and distribute licensed generic versions of Harvoni. The four licensed manufacturers are Cipla, Mylan, Natco Pharma and Hetero and all their products are chemically identical.”

In 2015, Jefferys flew from his home in Australia to Chennai, India. He purchased the generic meds and underwent his 12-week treatment there. Within 11 days his liver functions had returned to normal and within four weeks, there was no longer any virus detected in his blood. The trip and treatment cost him less than \$4,000.

I’ve dubbed Jefferys the Tasmanian Angel because after he learned where to find affordable lifesaving meds for his HCV, he reached out to help others. I asked Jefferys if he got the idea for helping HCV sufferers access generic pills from the movie *Dallas Buyers Club*. That’s when the Australian’s big, warm grin filled my monitor for the first time. “I watched the *Dallas Buyers Club* after I first started doing this. Watching it did give me a few good ideas.”

Unlike Ron Woodroof (Matthew McConaughey’s character in the film), however, Jefferys is not motivated by money. “When I first started helping people to access affordable hep C medicines,” said Jefferys, “I never thought it would become a full-time occupation. But it has. I don’t want to profit from people’s sickness, though. There is enough of that going on

already.”

Jefferys continued, “When I started off I didn’t think it was going to become such a big thing, so I did everything for free. When it started to take up so much of my time I told people, ‘Look, if you can afford to give me a small amount for my time that would be very much appreciated but if you can’t, that’s okay, too.’

“Now, if I handle a transaction from beginning to end where someone says, ‘I want you to do everything for me. I’ll send you the money. You send it to your contact. You organize all the documents.’ In that case, I say, ‘I’ll charge a fee for that, but if you can’t afford the fee, then you don’t have to pay it.’”

He told me of a woman he’s currently helping. “She’s from Serbia and her mother has hep C. I’m organizing everything for her and doing that at below my cost. In Serbia the income is like \$50 dollars a week. I don’t want to make any money at all on that transaction.”

What about the legalities? Jefferys said, “It is perfectly legal to go to another country, buy generic drugs, and bring them home. Things get sort of blurry when you get generics shipped to you. If you go to China and buy a box of counterfeit Ray Bans sunglasses and bring them home to the U.S. to sell them, that’s illegal. It’s a breach of patent law. But, if you’re in the U.S., and mail-order one pair of counterfeit Ray Bans from China and have them sent to you for your own use, that’s not illegal. It’s the same with generic drugs. It’s the difference between buying something to make a commercial profit or for personal use. I help people buy

medication for their own use; I am not selling it.”

Most of his work is giving people information, honest and reliable contacts in countries where they can buy generics, such as India, Bangladesh, Thailand, Australia and Honduras.

Why hasn't Gilead gone after Jefferys? He said, “I was told by a Gilead insider that when I first started doing this, Gilead got advice from a ‘crisis manager’ who told them that if they went after me, it would just generate bad publicity for them and make a martyr out of me so, apparently, they have just decided to leave me alone.”

And it's great that they did. Jefferys has gotten so involved in this issue that he was invited to the prestigious annual conference of the European Association for the Study of the Liver (EASL). Jefferys said, “It's been nearly a year since I was sitting on a plane flying over central Australia on my way to Chennai in India to find generic sofosbuvir. So much has changed since then. A year ago, my body was wracked with the hepatitis C virus.”

His eyes grew sad as he relived his ordeal. “I was exhausted most of the time and spent hours in bed every day. My blood was poison and even my wife was scared of accidentally coming in contact with a drop of my blood. I was scared to play with my grandson in case I infected him.”

Now his HCV is completely gone. He can swim, or walk in the mountains, for hours. On April 6, he flew to Barcelona, Spain for the 2016 EASL Conference being held April 13 to 17. He shared his story to

demonstrate how vital generic HCV medicines are, and was among top liver specialists including scientific researchers, medical experts, and advocates fighting for policy change on treating liver disease. Jefferys even co-authored a paper that was presented by Dr. James Freeman from the Department of Emergency Medicine at Royal Hobart Hospital in Australia.

Jefferys said, “I hope Dr. Freeman’s presentation made medical professionals, particularly liver specialists, aware of the importance of generics, especially the licensed Indian generic hepatitis C meds.”

Last year, Jefferys studied the 2015 EASL conference papers for up-to-date information on treating hep C. “It was a steep learning curve,” he said. “Before I was diagnosed in August 2014 I didn’t even know what hep C was.”

I asked Jefferys what he thought of Gilead’s defense that their profit margin is justifiable due to all of the time and effort put into research and development for these HCV medications. Jeffrey’s response? “That is just bullshit. They didn’t put any research into it. They bought a patent, a finished product, and they marked it way up.”

He has no problem with research companies making a profit, “but,” he said, “it has to be a fair profit.”

At the end of our interview I said, “You must have amazing karma now, after helping so many strangers.”

**The Tasmanian Angel said, “It’s a privilege, isn’t it? You don’t get a chance like that often. I guess once you’re my age, you look back on your life. I’ve had a good one, so it’s a great feeling to be able to give back.”**

