

LET ME

INTRODUCE MYSELF TO YOU AS A VICTIM of HEPATITIS C

with Geno Type 1B

BECAUSE

I received HEP C through Blood transfusions because I have a mild form of hemophilia.

I HAVE BEEN REFUSED A PLACE ON A TRIAL BECAUSE OF I HAVE MILD HAEMOPHILIA

I HAVE NOT BEEN ALLOWED TREATMENT, FOR NO GOOD REASON THAT I CAN SEE !!!

IT WAS NOT MY FAULT!!! IT WAS GIVEN TO ME THROUGH THE MEDICAL SYSTEM OF THE TIME IN A BLOOD TRANSFUSION AFTER SURGERY!!!

I SUSPECT I HAVE HAD HEP C SLOWLY GRINDING AWAY INSIDE ME DAMAGING MY LIVER FOR 40 YEARS , **AND WAS NOT MY FAULT THAT I AQUIRED IT.**

BLOOD TRANSFUSIONS 1972, 1976, 1983 & 1993.

WHY AM I DISCRIMATED AGAINST FROM BEING GIVEN THE OPPORTUNITY OF A FREE CURE because I am AWARE THAT OTHERS HAVE BEEN OFFERED A CURE FOR FREE. I have lived a good clean and disciplined life.

I NEED THE CURE NOW WHILE I AM RELATIVELY HEALTHY !!

IT IS JUST NOT FAIR:
IT IS MORALLY WRONG:

I CANNOT UNDERSTAND THE GOVERNMENTS STAND ON THIS POSITION:

I SAY “IT IS NOT A FAIR SYSTEM”!!

IT APPEARS DOCTORS ARE FORCED TO TREAT WORSE CASE SCENERIOS. PLEASE ALLOW TREATMENT FOR US BEFORE OUR HEALTHS DETERIORATE FURTHER.

I SEE THIS SCENARIO FREQUENTLY WHEN I VISIT THE LIVER TRANSPLANT UNIT IN MELBOURNE AND STAY IN A MEDI HOTEL AMONG THESE PEOPLE, SO I AM NOT TALKING THROUGH MY HAT.

AS WELL AS THE EXORBITANT FINANCIAL COSTS OVER THE YEARS VISITING A MELBOURNE CLINIC BECAUSE I LIVE 425 KMS OUT.... THE LONELY MENTAL PATH FOR MYSELF AND HUSBAND PLUS THE CONSTANT FATIGUE AND UNWELLNESS... HAS BEEN AN IMMENSE COST THAT PROBABLY THE READER WILL NEVER UNDERSTAND.!!!

ALSO – Too many blood tests to count
Too many liver scans to count
Too many anxious visits to specialists to count
Too many long car journey s to count
Too many, too many... will you comprehend ??

DISCRIMINATION

Over the years I have had many incidences that I have been the victim of discrimination hospital admittance where I was examined for scabs!!! Deposited at the end of a corridor in a lonely room after being transferred from a two bedroom ward after they discovered I had Hep C.

On another occasion sent to an infectious disease ward...

In the beginning 1990 placing great strain on my matrimonial relations because of risk of infection...my husband refusing to even kiss me until he understood the situation. THAT WAS A TERRIBLE TIME also he could not be convinced that he didn't have it too even though many blood tests on him proved he had not contracted the disease .. IT WAS ALL VERY VERY CRUEL !!!

MANY YEARS LATER... Refusal by the blood bank to take my husbands blood prior to his prostate operation because we shared a bed!!! HE DESPERATELY NEEDED A STORE OF HIS OWN BLOOD.!!

Even refusal of travel insurance because of HEP C status.

It is difficult for some members of family when I visit!

It's been a long haul... LET ALONE THE SAD EMOTIONAL JOURNEY OF 'LIVING THIS SECRET LIFE' BECAUSE OF FEAR OF DISCRIMINATION with only my husband and one friend to share the journey!!

THIS WEEK: FEBRUARY 2015

WHY DOES THE PATHOLOGIST WHO HAS KNOWN ME FOR MANY YEARS BECAUSE OF HAVING SO MANY BLOOD SAMPLES TAKEN, HAVE TEARS IN HER EYES AND GIVES ME A HUG AFTER MY GIVING MY BLOOD FOR YET ANOTHER LIVER TEST SAY:.

IN THIS TOWN THERE ARE THREE PEOPLE RECEIVING DRUGS TO CURE THEIR HEP C for free WHY ARE YOU NOT BEING INCLUDED ??

THERE IS EVEN ONE WOMEN in this town IMPORTING HER DRUGS FOR A CURE FROM AMERICA .

SHE TOLD ME – WRITE TO THE PRIME MINISTER – DO SOMETHING...IT IS JUST NOT FAIR AND YOU ARE BEING DISCRIMINATED AGAINST.

I AM A PERSON THAT HAS LIVED A GOOD CLEAN LIFE. NO ALCOHOL, NO SMOKING, MARRIED FOR OVER 50 YEARS TO THE SAME PERSON AND HE BEING MY ONLY PARTNER EVER!!! AND I HAVE NEVER HAD ANOTHER SEXUAL PARTNER - HOW RARE IS THAT THESE DAYS.

I HAVE BEEN VISITING THE LIVER TRANSPLANT UNIT AT A HOSPITAL IN MELBOURNE SINCE 1990 WHEN I WAS FIRST DIAGNOSED.

BURDEN ON THE HEALTH SYSTEM !!!

My grave concern for myself is...

Following are the readings of fibroscans I have had over the past four years.

March 2010	5.3
March 2012	6.8

March 2013 16.8 after 4 months flare of Hep C
March 2014 11.8

MARCH 2015 probably 12.0 PLUSgoing on the past statistics

This equates to a 5 year period.

In another 3 years if the deterioration is the same I will be a burden on the Health System and myself, a place I fear to go unnecessarily.

A reading of 16 is the end of the pier....turning to LIVER CANCER ..what an end, when I could be saved from this by treatment!!

FROM:

SUFFERING NOT ONLY TERMINAL CANCER
SUFFERING & PRESSURE ON MY FAITHFUL HUSBAND
SUFFERING LONELINESS AND SERIOUS DEPRESSION
BECAUSE OF TYRANNY OF DISTANCE FROM HOME
RELATIVES
FRIENDS

Suffering a long, slow and painful death, filled up with drugs, a burden on myself, society AND THE HEALTH SYSTEM !!!

IT'S A SAD END THAT COULD BE PREVENTED !!!!

To look in the bottom of a dug grave and know your ending is pretty tough stuff !!!

When it need not be.....

I am currently a much needed small town volunteer and active community participating in many activities.

I do not drink Alcohol, I have never smoked, we live in the country, food has always been home cooked and healthy. I have been married to the same man for over 50 years, he has never contracted Hep C

MY LIFESTYLE IN TODAY'S TERMS IS VERY GOOD.

I REITERATE THIS POINT .. We have been put up in a Medi Hotel at a Melbourne Hospital many many times for which we are very grateful. Over this time we have shared many community meals and chats over their dinner table.

We have talked to many many patients in various stages of liver treatment, some having had transplants, some waiting to have a transplant, some being measured up, some my age looking many many years older than myself.

They ask the question, why am I there, and in return I ask why are you there. Quite a few transplant patients have openly admitted to me they are travelling their journey because they ruined their livers with 'the high life' when they were younger.

Therefore the big question in my heart is why should I be refused free treatment with these new drugs because I have lead a good healthy life, not partaking in a lifestyle that is detrimental to my health. **It really does seem quite unfair.**

I therefore am putting this to whoever it may concern...to really think about it..

Treatment now would put an end to my being a burden on the health system, my husband, myself, and my family and my community. Travelling 10 hours plus return travel time for each check up. I really think people like myself should be given fair consideration by all the members of your Advisory Committee when the decision is made regarding making this treatment available to people who have received this hideous disease through blood transfusions.

And or allow treatment to those who are NOT yet on death's door !!

In closing I also would like to state that at no time should I be disadvantaged by the distance I live from Melbourne if I was to be offered treatment 12 weeks etc.

I would come down and live in Melbourne for the time of treatment, in a loaned caravan that has its own amenities within, that can be placed in a caravan park within close proximity of the Melbourne Hospital. I would therefore not be taking up accommodation needed by other Liver Patients.

Thank you so much for reading

Also to be noted...I take minimal other drugs

Coversyl 10 mg for High Blood Pressure

Diabex XR 1000mg 1 tab am 1 tab pm

Average Blood Sugar Reading over last 3 months 7.

Noting Diabetes will continue to increase as a problem because of Hepatitis C and therefore another burden on the Health System.

ACCESS TO NEW TREATMENTS WOULD :

CURE ME

LET ME LEAD A LIFE WITHOUT DISCRIMINATION

LET ME LIVE A NORMAL LIFE WITH OUT ANXIETY

LESSON THE DEPRESSION & FOGGY BRAI SYNDROME

I WOULD NOT BE A BURDEN ON THE HEALTH SYSTEM

I WOULD NOT CLOG UP THE LIVER TRANSPLANT UNIT

MY LIVER WOULD BE FREE OF DISEASE AND I WOULD BE HEALTHIER, I COULD ANTICIPATE A LONGER LIFE!!

WHAT A JOY !!

A real chance of a cure! The new drugs are interferon free.

No threat of liver cancer in 3 years because of present high fibrescan reading of 12 plus16 is liver cancer

Improved diabetes because of healthier liver

Extended 15 years or more of life.

Relief of 40 years of stress and anxiety on my husband and myself

Relief of peripheral neuropathy caused by stress!!

A NON foggy brain ...would be wonderful!

If I am cured

Relief from debilitating fatigue, depression and other horrible symptoms, especially foggy brain.

Relief of emotional and financial pressure on both my husband, myself and family.

Will be able to live in our own home in our country town, not having to travel long distance to Liver Transplant Unit in Melbourne.

Not have to anticipate a Liver transplant...

Not have to live in fear of the future

It would be available to people like myself and be accessible locally away from major city hospital clinics..

It is presently so unreasonably out of financial range.

We would not be a burden on the Health System long term as is our future now.

If it develops into liver cancer and liver transplants - this is nearly unthinkable for country people BECAUSE OF DISTANCE FROM LIVER TRANSPLANT CENTRE!!.

If it requires a Liver Transplant, in the country expense to self would be so prohibitive it probably couldn't happen.

Would have to be a saving long term on the Government & Medical System eradicating Hep C in the future

It would let Doctors treat others who would not have these options and free up hospitals, waiting rooms, and pathology tests and etc for other uses.

I JUST HOPE SOMEONE HAS TIME TO READ MY STORY. AS A LAY PERSON ITS DIFFICULT TO PUT MY OPINIONS, THOUGHTS & FEELINGS INTO SUITABLE HEADINGS, BUT APPRECIATE THE FACT THAT I CAN TRY AND HOPE IT HELPS YOU UNDERSTAND MY POSITION.

WE NEED THIS TREATMENT TO BE ON THE PBS URGENTLY

THANK YOU

Extra notes

In the latest news available, other countries in the world are trying to

'make deals' with the drug companies to purchase drugs that will cure the hepatitis community for lessor amounts of money because of quantity required. And also to help their health funds cope with epidemic demands for these new drugs...

**Why can't the Australia government do something similar.
Why can't the Australian government direct their attention to those of the haemophilia community to treat this long suffering group with free drugs!**

We really only want a fair deal!!!

The history of how this disease has gotten into the system for blood transfusion is being swept under the carpet.

Those of us that this disease is affecting, have sat quietly on the sidelines for years need to get up steam and be vocal, in a way that excludes us from discrimination. This is nye on impossible so that is why we sit quietly watching, waiting and suffering our situations!!

ARE THERE ANY SUGGESTIONS TO STOP/REDUCE STIGMA & DISCRIMINATION?

The first answer is to be FREE OF DISEASE

Going from the misunderstandings in my family among non medical people the stigma and discrimination is so deeply ingrained the situation seems hopeless !! I wonder if anyone would try to understand – they don't at the moment all is swept under the carpet and no one will discuss my situation!!!

UNLESS

There is a huge publicity program for those that can be and are cured by low cost or free access to drugs that will cure.. as they are considering in other countries across the world!!

Thank you to those who are working on our behalf!!!