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BC's Hepatitis C News Bulletin

"Promoting HCV Wellness"

February, 1997

MEET RON

I had an interesting talk on the phone the other day with Ron Thiel, and I asked him if he would be so kind as to contribute his comments to our newsletter, since what he reports is significant, I believe, for our members who may be seeking legal justice for transfusions prior to the date specified by the lawyers in the present class action suit. He did so, and this article is the result:

"Recently I was clearing out various papers and found one that I had kept as a souvenir of the Captain Cook Bi-centenary. On looking through it, I realized that just the cover pages were of any interest and was about to throw the rest out when I came across the enclosed article regarding Hepatitis. The date seems significant. (See attached article.)

In 1983 it was discovered that I had a birth defect in my Aortic heart valve and the valve was replaced in August of that year. By 1988 I started to experience fatigue and pain around the liver area. Eventually I was told that I had Hepatitis C. The first question my doctor (and the many other doctors I have seen since) was "Have you ever had a blood transfusion?"

By 1994 the replacement valve was starting to show signs of wearing out, and after two prolonged bouts in hospital, it was decided, early in 1996, that I had to have surgery again. This took place in May, and two valves were replaced. Prior to the surgery I asked my surgeon if I could make an autologous blood donation, and he stated that the "safest blood is your own blood." Although he had no objection, he felt the blood bank would reject my request, which they did. I talked to the doctor in charge of the Royal Jubilee Blood Bank, and he told me that I was rejected because I had Hep C. I said that that was ironic, as I had been infected with it from tainted blood in the first place. He informed me that mistakes in labeling could still be made and somebody else might end up with Hep C from my blood. My daughter had offered to provide the necessary blood but this too was rejected as it was considered to be "jumping the queue", although she would have only been taking my place. The doctor also said, "I suppose that there is no use in trying to convince you of the safety of the blood supply" to which I replied, "None whatsoever."

Prior to surgery, I had to consult with one of the resident physiotherapists, and when I advised him of my condition, he told me he had recently seen three or four other patients who had their original surgery about the same time as I did who also had Hep C, so it seems that it was fairly prevalent in the Royal Jubilee in 1983.

After my surgery, I developed an infection, lost 30 lbs., became jaundiced, suffered a build up of fluid, and ended up in hospital again facing surgery on an abcess in a very embarrassing place. All this has delayed my recovery and made life pretty miserable, and I feel sure that most of these problems can be attributed to the effect that Hepatitis C has had on my immune system."

Ron Thiel

[1978 article:] HEPATITIS AGENT: THEY'VE NAMED IT FOR WHAT IT ISN'T.

From the ***DAILY COLONIST***, Victoria, B.C., Wed., March 29, **1978** page 54:

WASHINGTON (AP) -- U.S. scientists say they have the first hard evidence that a previously unknown infectious agent, probably a virus, is responsible for most of the hepatitis people get from blood transfusions.

A report this week said the agent, not recognized as a separate disease entity until recently, had become the most prevalent cause of post-transfusion hepatitis.

This side effect of transfusions, which still affects an estimated 150,00 to 200,00 persons a year, has decreased by 90 per cent in the past 10 years because of a wide effort to eliminate commercial blood-collecting, the chief source of viruses previously known to cause the liver ailment.

But post-transfusion hepatitis persists, and scientists say the new agent is the culprit.

In the past, the principal cause of post-transfusion hepatitis, once known as serum hepatitis, was a virus called type B. Another less severe virus, called type A, was also implicated.

Tests developed in recent years to screen for evidence of these viruses eliminated them as the cause of most of the remaining post-transfusion hepatitis, indicating that another agent or group of agents was involved.

Because scientists don't know what the agent is, they named the new form of the disease "non-A, non-B hepatitis" for what it isn't.

Scientists of the National Institutes of Health and the food and drug administration found in independent studies that the new agent was infectious and transmissible to chimpanzees from human blood.

"This is the first concrete evidence that a virus or virus-like agent is involved," said Dr. Edward Tabor of the FDA. "Earlier evidence was circumstantial."

Scientists say the non-A, non-B hepatitis has a long incubation period of five to 12 weeks after transfusion before signs of it show up. Like type B hepatitis, the disease can be fatal in a few cases, and there is evidence people can carry the disease and transmit it without showing symptoms.

About 20 per cent of viral hepatitis victims can become very ill with liver inflammation, and the disease can lead to liver failure and the death of some tissue in several cases. There is no cure, but most patients recover after the disease has run its course.

[NOTE: 1978 date of above article]

AMANTADINE TRIAL UPDATE

Eyebrows were raised this summer when Jill Smith introduced the results of her Pilot Study with Amantadine. Skepticism prevailed but her results were encouraging enough to lead many of us to consider its potential use as a cheaper, less toxic, and more effective treatment than Interferon. I for one took the initiative to call Dr. Smith to inquire about her study. An appointment was made in August of 96 and to Hershey Medical Center I drove. In meeting Dr. Smith I found her to be engaging, honest and forthright. She offered no panacea but a chance to combat my disease, a chance that on two different occasions Interferon did not provide. I took her offer and began my daily regimen of Amantadine 100mg twice a day. The prescription cost $26.00 for 1 month supply. The medication came in small red geltab form which is easily swallowed. After my first day the only obvious side effect I had was slight jitteriness akin to the feeling one might get from a cup of strong coffee. Hence forth aside from a few restless nights I would be put to task to come up with any other discernible side effects. After my first month my lab results were encouraging my ALT had gone from 2x normal to almost normal. Dr. Smith issued a caveat though stating that despite the improvement my high starting viral load [23 mil] may ultimately make me a non-responder. Since then I have seen essentially no change in my LFTS nor my viral load but the one change I have seen is in the way I feel. I can honestly say that I feel better now than I have in years. Now one could argue that the effect is placebo but none the less it's true. Today was my fifth appointment with Dr. Smith. I took with me copies of some of the recent comments citing skepticism regarding the efficacy of Amantadine therapy. In view of my questionable response I too harbored skepticism but I left her office with renewed hope that Amantadine may still be the key to my recovery. My reasons are as follows:

To date according to Dr. Smith there has never been any human studies published regarding the treatment of HCV with Amantadine. In fact she stated the only published report involved rats infected with the hepatitis virus and the results were highly successful In defense of Dr. Smith I would challenge anyone to have their doctors produce a report to the contrary.

Of the non responders in her first study by increasing their dose to 100mg 3x a day or by extending treatment lengths they have now become responders.

Of the 6 who initially cleared the virus 2 relapsed after 12 months and then cleared again after retreatment.

She states categorically in no uncertain terms that Amantadine is working. She also states that there is still much to be learned of its mechanism of action in treating HCV but plans are underway to establish that role.

She states this may not be the treatment of choice for everyone but thus far no exclusion criteria has been established.

What she does know is that histology has not been a factor. Whether or not genotype is remains to be seen but she doubts very much that it will be.

By the way, it seems Dr. Smith prefers that her patients all use Symmetrel. There is no real basis for that decision other than the fact that Dupont who developed amantadine produces Symmetrel. With that she believes you are ensured of receiving the genuine article not a second rate imitation. She's just playing the odds which is not a bad idea for any of us.

No one wants to cling to false hope but I think we must have our facts straight to make reasonable decisions about all treatment options. I'm not advocating Amantadine as the great hep hope but I have faith in Dr. Smith's word and her work.

I hope this served to answer some questions and alleviate doubt about the ongoing Amantadine Study.

To be honest with you, going on Amantadine was a no brainer. If I was crazy enough to stick myself with a needle 3x a week for 16 months total and make myself sick what's the big deal in taking a small red pill 2x a day. You never know it just might work.,,,,,,,,,,,,dan

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BRAZIL'S ORGAN DONATION BILL

BRASILIA (Reuter) - Brazil's Senate Thursday approved a bill
that aims to resolve a shortage of organs available for transplant operations by making all Brazilians potential organ donors, an official said.

The bill, which has to be signed by President Fernando Henrique Cardoso to become law, would allow authorities to use organs from bodies, unless specifically instructed not to do so on the identity cards or driving licenses of the deceased.

``Brazil suffers from a lack of donors and paperwork that makes organ-donation complicated,'' said Sen. Lucio Alcantara, who drew up the bill.

About 60 percent of the 25,000 Brazilians receiving dialysis treatment for kidney disease could be cured if kidneys were available for transplant operations, he said.

The bill would also require the government to carry out annual campaigns encouraging families to offer the organs of dead relatives for transplant, he said.

The Order of Brazilian Lawyers (OAB), which consulted Congress on the bill, was split on the issue, with some members arguing it was an infringement of civil rights.

But OAB acting president Safe Carneiro, who told a congressional panel he favored the bill, said the new legislation would save lives and help stamp out illegal trafficking of organs.

``We have a vast pool of hospital patients who desperately need organs and face death because some people consider the corpse of their loved ones sacred,'' Safe said. ``This bill is of the utmost importance.''

NEXT MEETING:

Wednesday, Feb. 19 , 1997 1 - 3 PM, and again at 7-9 PM St. John the Divine Church Lounge 1611 Quadra St. (Entrance through the rear, marked Annex)

COMING THURSDAY, FEBRUARY 13, 1997 from ITV (Information Television Network) a television report devoted exclusively to Hepatitis C, airing on The Discovery Channel. Be sure to watch!

DID YOU KNOW.....ABOUT TAP

The Travel Assistance Program is sponsored by the BC Ministry of Health and Ministry Responsible for Seniors.

TAP was created to help residents of BC to access health care services that they cannot obtain unless they travel.

In other words, if you have to travel to get access to specialists in Vancouver, for example, the TAP program will pay for, or give you discounts for your travel costs, such as ferry fares, for you, your vehicle, and for an escort, if one is needed.

Please ask your doctor for a form to complete. You also need to contact MSP to verify your eligibility and to receive a confirmation number before you travel. (Phone number below)

You are eligible if you are a BC resident enrolled in the Medical Services Plan, and your travel expenses aren't covered by other insurance policies. There are regulations such as arriving at the ferry, for example, one hour before departure.

This program doesn't include meals, accommodations, car expenses, or local transportation. You must make your own travel and accommodation arrangements. You may obtain more information by calling MSP at 1-800-661-2668 from 8:30 am to 4:30 pm, Monday through Friday. You may also call 387-8277 in Victoria.

The deadline for any contributions to next issue of hepc.bull is February 23rd. Please contact Joan Diemecke at Tel. 479-5290.

DEALING WITH PAIN

Some medical experts suggest food strategies for avoiding pain:

Notice the way your body responds to food. Do you feel tired after eating low-fat meals, such as a bagel, or cereal with skim milk? Request that your doctor check for insulin resistance. Do you have sore muscles or joints? If you try eating mostly plant-based foods for a week, and do aerobic exercise for a half-hour each day, you may be in for a pleasant surprise.

Stay away from cola drinks. Cola has been called "the perfect deadly food"--coloring, sugar and caffeine. Buy yourself some juice instead.

Avoid milk. Get calcium from greens and other high-calcium foods, like tofu, instead.

Eat fatty fish (mackerel, herring, salmon). The Encyclopedia of Natural Medicine states that those fish increase your level of eico-sapentaenoic acid, which in turn decreases the release of pain-inducing arachidonic acid into your system.

If you are experiencing pain and cannot find the exact cause, try consulting a doctor who practices environmental medicine.

Avoid all processed foods and all animal foods. Get plenty of rest. Otherwise, you're going to pay the price.

DISCLAIMER:

HeCSS cannot endorse any physician, product or treatment. The guests invited to our group to speak, do so to add to our information only. What they say should not necessarily be considered medical advice, unless they are medical doctors. The information you receive may help you make an informed decision. Please consult with your health

practitioner before considering any therapy or therapy protocol

RECIPE CORNER: MAGIC MEATLESS CASSEROLE

2 cups cooked brown rice
l cup water
l cup sliced celery
1/2 cup chopped onion
2 tbs. vegetable oil
l (540 ml) can of stewed tomatoes
2/3 cup chopped pitted olives
227 g. gourmet tofu burgers (cubed)
2 tbsp. all-purpose flour
2 tsp. chili powder
1 tsp. salt
1/4 tsp. garlic powder
l cup frozen peas
2/3 cup soy or rice cheese (shredded)

1.) In a saucepan, over medium to high heat, cook celery and onion for approximately 5 minutes. 2.) Add tomatoes and olives, bring to boil. 3.) Meanwhile mix flour, seasonings, and water in a separate bowl. 4.) Add to hot mixture, stirring briskly. 5.) Cook for 3 minutes to thicken sauce. 6.) Add frozen peas and cubed tofu. 7.) To assemble, pour half of the sauce mixture into a 2 L. casserole dish. Top with the cooked rice and remaining sauce. Sprinkle with shredded cheese substitute. Bake at 350 degrees F(l80 degrees C) for about 20 minutes.

(Brown rice freezes extremely well This recipe can be assembled quickly. if you already have some frozen rice on hand. Add a green salad and you have a great dinner on those snowbound winter evenings!) BON APPETITE !
RECIPE CONTRIBUTED BY JP

FROM THE MEMBERSHIP DESK

Your Steering Committee is planning an awareness program in the community, so watch out for details in future Newsletters.

We still need you to consider becoming members as this gives us much more clout. Why not complete the Application Form (if you have mislaid it, phone for one) today and mail it to the Toronto Address.

Reminder:- Any change of address, phone number, or Postal Code, please let me know at your earliest. It saves us money. Thanks.

Jim Lodge 386-8227
Co-chairperson Membership Chair

A NOTE FROM DAVE

Hope. It is just a simple four-letter word. When you really think about it, though, it becomes more than that. When you feel like you've been run over by a Mack truck, and your doctors are dismissing your symptoms as "all in your head", and your liver enzyme numbers are flying through the roof, the word "hope" may not even be a part of your vocabulary.

However, if you just take a moment to ponder upon this little word and savor its meaning, you might see that all isn't lost in your life and your world isn't turning upside down after all.

Take, for example, our friend Joe, who was diagnosed HIV positive in 1985. About the same time I was diagnosed with Hep C, he acquired full blown AIDS. He was a flight attendant with houses in Vancouver, Paris, and Toronto, and it was decided after he got really sick that he would stay in Toronto.

I was spending a lot of time in Vancouver by this time and we were using his house as a place to reside while we were there. For myself, it was a very strange situation, being in a house owned by a family friend who was dying of AIDS

while I was dying of end stage liver disease.

As time went by, it looked like both of us were not going to make it. Joe was given "last rites", New Year's Eve of 95-96, about the same time I was recuperating from my own miracle liver transplant.

Getting back to our original topic, though, about never giving up hope, we got a phone call the other night from Joe, saying that his doctors had given him a clean bill of health, and that the virus had cleared his system.

How did this happen? Most definitely, the new series of cocktail drugs had a great deal to do with it. Let's call it AZT plus, being as I don't know at this time what the combinations were.

I think, though, that attitude has a great deal to do with it. Never giving up hope; creative fighting without the anger along with a strong faith and a lack of fear of death. These things you may not even be entirely aware of or unable to articulate, but if you give up on yourself -- give up "hope" -- then those other things may not work for you, either.

Yesterday there was so hope for Joe. Today, he is thriving. You can apply the same to hep C patients that today there is no cure, but tomorrow there may be, so don't give up!

COORDINATING COMMITTEE -- VICTORIA CHAPTER

CO-CHAIRS:	JIM LODGE	TEL: 386-8227	
	DAVID SMITH	TEL: 658-4991	
	RYTA TRACY (on leave)	TEL: 475-1860	
SECRETARY	(vacant)		
TREASURER	FRANK NIELSEN	TEL: 727-7172	
MEMBERSHIP	JIM LODGE	TEL: 386-8227	
LIBRARY	JOANNE BALCHIN	TEL: 478-2356	
BULLETIN	JOAN DIEMECKE	TEL: 479-5290	(TEL. & FAX)