

Canada's Hepatitis C News Bullet www.hepcbc.ca

BREAKING NEWS:

SIMEPREVIR APPROVED IN CANADA!!!

NOV. 20, 2013 (SEE PAGE 2)

CLINICAL TRIALS

FALDAPREVIR (FDV) 84-97%

FDV+ pegylated interferon/ribavirin (PR) (STARTVerso1 & STARTVerso 2 trials) showed a better SVR12 rate (83-88%) compared to PR alone regardless of GT subtypes, IL28b types, amount of scarring, viral load, race, GGT level and all usual causes of failure, perhaps including management of adverse events (AE). 24 weeks of FDV+PR produced the 88% SVR rates in treatmentnaïve patients with early response rates, and an overall rate of 73% in all patients, with the higher dose. FDV was more easily tolerated than the 1st generation of PI's (protease inhibitors).

FDV is also being studied in IFN-less combo clinical trials with deleobuvir (DBV), a non-nucleoside polymerase inhibitor. The SOUND-C3:FDV+DBV +RBV produced SVR12 rates of up to 95% in GT1b's. Early data from a Phase II with FDV +DBV+ PPI-668 (an NS5A inhibitor) in difficult to treat GT-1a's showed a RVR in 97%.

Source: AASLD 2013 Nov 1-4 Wash DC (Jules Levin, natap.org)

SOFOSBUVIR+LEDIPASVIR 95-100%

Encouraging interim data produced 97% non -detectable rates after 8-12 weeks of treatment from a Phase II LONESTAR study of Gilead's sofosbuvir (SOF) and ledipasvir (LDV) have opened the doors for Phase III studies. The Phase II trial treated 100 GT1 patients, with or without RBV. There were 5 arms: 3 arms were treatment-naïve patients. 1 of those arms studied SOF+LDV for 8 weeks,

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TREATMENT TIPS: GETTING READY FOR THE BIG DAY

I completed 28 weeks of Triple Therapy in July, 2013. It was one of the most difficult things I have ever done, yet at the same time, one of the most rewarding.

When I was first diagnosed back in 1997, I was told this was a life sentence, that it was incurable...yet here I am, 16 years later, 3 months post TX and undetectable.

When I received the stack of "possible" side effects. I was overwhelmed. I had read up on treatment but had no idea of the magnitude. As my start date got closer, I began to feel more and more stress around the burning question. "What will it be like for me?"

I found that the best way to manage my anxiety was to create a list of things to organize and buy, that might help to make the journey easier. To that end, I have put together a list of preparations that worked for me, as well as tips I gathered along the way.

Please be advised: Before taking any medications or supplements, check with your health care professional to make sure they are safe for your situation and do not conflict with medications you are (or will be) taking. Always read the labels and discuss any concerns with your doctor, pharmacist or health care professional.

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TREATMENT THROUGH CLINICAL TRIALS BY ALP

I have been on several treatments for HCV (genotype 1a) between the years 1999 and 2013. I have lost track of how many, but it would be safe to say I have been in 6 clinical trials and a couple of prescribed treatments. I never had a documented viral load drop of 2 log, though I had completed a couple of treatments before they started measuring viral load during treatment, and so I became labelled as a null responder.

The pros of clinical trials:

- ♦Paid for by pharmaceutical companies, they are free or even offer a small payment to the participant.
- ◆Costs of all tests are included.
- ♦You may be cured.

The cons are many:

- ◆The drugs are still experimental. Depending on what stage the trial is at there will be more or less data available on safety and efficacy.
- ♦You may end up worse off. There have been some serious adverse effects from some trials.
- ♦You may risk developing a viral population that is resistant to the class of medication you are trying, due to sub-optimal dosing or a less than efficient drug.
- ♦You may be in the placebo arm.
- ♦You may be in an arm that provides only one or two drugs out of a multidrug cocktail which might prove to be sub-optimal and lead to viral breakthrough and viral resistance to future treatments.

After about 12 years of trying to beat HCV and suffering from several "non-hepatic symptoms" which made things very uncomfortable at times. I decided to try to get into clinical trials further from where I lived. The United States often has trials that are not offered in Canada.

In 2011 I applied for admission into a trial for BMS-790052 and PSI-7977 an NS5a inhibitor and a polymerase inhibitor. The

(Continued on page 3)

SUBSCRIPTION/ORDER FORM

Please fill out & include a cheque made out to **HepCBC** - Send to our **NEW** address:

HepCBC 2642 Quadra Street PO Box 46009 Victoria, BC V8T 5G7

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(Note: The hepc.bull is mailed with no reference to hepatitis on the envelope.) You may also subscribe or donate on line via PayPal at www.hepcbc.ca/orderform.htm
Download the hepc.bull free at http://hepcbc.cg/hepc-bull-monthly-newsletter/

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LETTERS TO THE EDITOR:

The *hepc.bull* welcomes and encourages letters to the editor. When writing to us, please let us know if you *do not* want your letter and/or name to appear in the bulletin.

SOFOSBUVIR (SOV)TRIALS

Genotype 3 HCV

- In the Phase 3 VALENCE study, 84.8% (n=212/250) of treatment-naïve or experienced patients with genotype 3 HCV who received a 24-week regimen of SOV + RBV achieved SVR12. SVR12 is considered a cure for HCV infection.
- In the Phase II LONESTAR-2 study, 83.3% (n=20/24) of genotype 3 patients who failed previous therapy achieved SVR12 after receiving 12 weeks of treatment with SOV/RBV/IFN.

Significance: There are currently no effective treatment regimens available for genotype 3 HCV patients who have failed prior therapy. Results from VALENCE and LONESTAR-2 show sustained viral response data for SOV-based regimens in these patient populations.

Source: <u>www.businesswire.ca/news/ca-en/20131102005008/en/Gilead-Announces-</u> Sustained-Viral-Response-Data-Sofosbuvir-Based

HCV/HIV Co-infection

• The Phase 3 PHOTON-1 study evaluated an IFN-free 24-week regimen of SOV/RBV among patients with HCV/HIV co-infection, the vast majority of whom were also receiving antiretroviral therapy for their HIV infection. 76% (n=87/114) of genotype 1 patients achieved SVR12.

Significance: Up to one-third of people living with HIV are co-infected with HCV. People living with co-infection experience complex health outcomes. Current IFN-based HCV therapy is associated with suboptimal cure rates in these patients and can have significant interactions with HIV drugs.

Source: <u>www.businesswire.ca/news/ca-en/20131102005010/en/Gilead-Announces-</u>
<u>Phase-3-Results-All-Oral-Sofosbuvir-Based</u>

SIMEPREVIR (SMV)

Simeprevir (SMV) is a protease inhibitor developed by Janssen and Medivir to treat genotype 1 (GT1) patients. Phase II studies QUEST-1 and QUEST-2 enrolled treatmentnaïve patients, PROMISE treated relapsers, and ATTAIN treated null-responders (NR). New drug applications have been submitted in Japan and the US. Parallel studies are being conducted for HIV/HCV and HCV GT4 patients. SMV is being tried in IFN-free trials combined with Janssen's TMC647055 boosted with ritonavir (with GT 1a and 1b patients), with Gilead's sofosbuvir (GS-7977 or SOV) for treatment-naïve and NR GT1 patients, and with Bristol-Myers Squibb's NS5A inhibitor daclatasvir (BMS-790052 or DCV) in treatment-naïve and NR GT1 patients. SMV is also being combined with Vertex's VX-135, a polymerase inhibitor, in a Phase II trial, and plans to combine SMV with TMC647055 and Idenix's IDX719, an NS5A inhibitor, with or without ribavirin (RBV).

Results from two Phase III trials showed an SVR 12 (sustained viral response at week 12 after the end of treatment) of 80 and 81% in GT1 treatment-naïve patients when combined with pegylated interferon + ribavirin (PR), compared to 50% of those taking only PR. In some QUEST arms, based on the response of the patients, treatment was shortened to 24 weeks in 91%, resulting in an 86% SVR12. In patients with IL28B TT allele, the response rate was lower (65 and 58%). Among those with fibrosis F3 and F4, SVR12 rates were 70 and 66%.

Source:

www.medivir.se/v5/en/uptodate/pressrelease.cfm? releaseid=72412F94F36912C1&year=2013

[Editor's note: In places where SOV and SMV are approved individually, some specialists are prescribing them together, off label, because they produce SVR12 rates of over 95%.]

Pre- and Post-Liver Transplant Patients

• In a Phase II study (Study 2025), patients awaiting a liver transplant received up to 48 weeks of SOV/RBV, and among those with undetectable HCV (<25 IU/mL) at the time of transplantation, 62 per cent (n=23/37) achieved a virologic response 12 weeks post-transplant (pTVR12). In a second Phase II study (Study 0126) among post-transplant HCV patients, patients with established recurrent HCV infection following liver transplantation received 24 weeks of SOV/RBV. To date, 77% (n=27/35) have achieved SVR4.

<u>Significance</u>: Currently, all HCV patients with active disease experience HCV recurrence following transplantation. In these studies, SOV demonstrates the potential to improve patient outcomes by either preventing or effectively treating recurrent HCV infection following liver transplantation.

Source: www.businesswire.ca/news/ca-en/20131102005012/en/Gilead-Announces-Phase-2-Results-Sofosbuvir-Based-Regimens

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(THROUGH CLINICAL TRIALS-Cont'd from p. 1)

dosing was for 12 weeks. After numerous failures on 48 weeks of treatment I had doubts 12 weeks would be enough for all patients (I still do). They accepted me. I went down to San Diego and had a medical at the clinic. Somewhere during the week or 2-long screening process, I came across some data from a study that showed poor results from PSI-7977 + ribavirin for 12 weeks in non-responders. I decided to withdraw from entering the trial, as I had doubts 12 weeks would be long enough, even though it was a different combination of drugs and I thought it would be more effective than PSI-7977 with ribavirin. I found that they had extended the dosage from 12 to 24 weeks shortly after I had withdrawn. I have been kicking myself since.

Gilead bought Pharmasset, the maker of PSI-7977. In early 2013 when I saw they were holding trials, I asked to be considered for a non-blinded GS-7977 + GS-5885 trial (polymerase and NS5a inhibitors) with or without ribavirin for 12 or 24 weeks. There was a chance I could be in the 12-week arm with only 2 antivirals, but as the trial was un -blinded, I would know which arm I was in. One can drop out of a study if one wishes to at any time. I decided to do it. States holding this trial included Texas, Washington and California and I contacted trial centers in these states. I was accepted for screening at the San Diego / La Jolla Clinic, and went down for a medical and blood draw. I was later notified I had passed screening and was given a date for a pre-dose clinic visit. I also had to have a liver biopsy done at the clinic. As there was blood work each week for weeks 1 through 4 it made sense for me to stay in San Diego for 4 weeks and then return for future blood draws on 2 day visits, which has worked out well for me. Before I started dosing I was told I had been randomized to the 24 week, GS-7977/GS-5885 and Ribavirin arm. Triple combo for 24 weeks! Winner, winner, chicken dinner!

I have completed dosing and, as of my week 12 post treatment blood tests, I am still undetectable for HCV virus.

I had no trouble crossing the US/Canada border for the trial, but I would strongly recommend that you get a letter from the doctor at the trial site that states you are a participant in a medical trial, site address, contacts at site (doctor, nurse, study coordinator), duration of the clinical trial (from date, to date) and that your condition is not a danger to the public. I would also strongly advise anyone leaving their country for entry into a clinical trial to be certain that they

do not have anything on their record that would cause an objection at Customs when they cross into the country holding the trial. It would be a shame to get part way through a trial only to be found by an extra cautious Customs officer to have something on your record that disallows you from entry. This could jeopardize your treatment.

If you are thinking of travelling in order to get into a clinical trial, here are some things you may want to consider or do:

Apply to more than one site if possible. Clinicaltrials.gov often has one contact for each trial, but some trials may have more than one contact listed. You can also find possible trial sites on your own, through search engines, and contact them directly.

Get supporting documentation from the clinic to show Customs officers in case they want proof of why you are entering the country. Get supporting documentation for the clinical trial drugs you will be travelling with.

Make sure you will be allowed to bring back your trial medication. I am not sure of the rules covering experimental drugs, if those drugs are available in Canada. Mine were NOT available in Canada, except for the ribavirin, but I had no trouble with the ribavirin or the other clinical trial drugs.

Where is the clinic. Is it close to public transportation? It may be impossible to get a hotel room close to the clinic.

Are you well enough to travel and will your current medical condition cause you issues while travelling?

Will the trial drugs cause side effects that will make travel difficult?

Can you afford it? (Hotel, travel, food.)
Are you staying there for the entire clinical trial duration, or are you returning home between clinical visits? There are rules about how long a visitor can stay in certain countries.

If you are interested in getting into a clinical trial, you can do so through the website at http://clinicaltrials.gov/ You may type in a search for the type of trial you are interested in, for example, HCV, and modify your search by including what countries or states you are interested in.

You will usually get a list of trials. If the trial is recruiting it will have a CONTACTS area with whom to contact for more info or to apply to be accepted into the trial.

If you do some extra research with a search engine like GOOGLE, it might be possible to find out telephone numbers or email addresses for clinics offering trials.

If they are interested in you, you will have to supply some medical records and medical history to get into the trial, especially if you have been in a previous trial or treated for the condition previously. I usually get copies of my medical tests and procedures, but anything I did not have I was able to get from my doctors or the local clinic I frequent.

If the clinic is supplying you with drugs to take and you have to cross the Canadian border, you should be aware that there are rules as to what drugs can be brought into Canada. I had no trouble with my drugs. The odd time I was asked I showed them the letter and they inspected the labelling on the bottles which should be made out with your full name and what is in the bottle, if possible. You may want to contact Health Canada and discuss what details you can before you come back with study medication. You can find out more info about cross border meds at www.hc-sc.gc.ca/dhp-mps/compli-conform/ import-export/gui-0084_biu-uif-eng.php or:

Health Canada Address Locator 0900C2 Ottawa, Ontario K1A 0K9

Email: *Info@hc-sc.gc.ca* Telephone: 613-957-2991 Toll free: 1-866-225-0709 Fax: 613-941-5366



(CLINICAL TRIALS—Continued from page 1) another added RBV for the same time, and another arm used all 3 drugs for 12 weeks. The other 2 arms treated NRs (nonresponders). 1 arm used SOF+LDV for 12 weeks. The other arm used SOF/LDV/ RBV, also for 12 weeks. SVR8 was 95% in SOF/LDV for 8 weeks, with one relapser. (SVR12, or non-detectable virus 12 weeks after the end of treatment, is considered a cure.) SVR4 was 100% in treatment-naïve SOF/LDV/RBV for 12 weeks. SVR4 was 100% for treatment-naïve patients taking treatment for 12 weeks, with one cirrhotic patient who relapsed. SVR4 was 95% in the NR group taking SOF/LDV/RBV. One person wasn't available for follow-up. Several Phase III trials are underway.

Source: <u>www.hepmag.com/articles/</u> sofosbuvir LONESTAR 2501 24743.shtml

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(TREATMENT TIPS—Continued from page 1)

Pre-Treatment Tips

Appointments

Dentist

- A) If you are due for a cleaning or work, do so before treatment, as the medications, especially IFN, can make our bodies vulnerable to infection.
- B) During treatment, mouth and gums can be tender. If your teeth are cleaned and in good shape, it can reduce your discomfort.
- C) If you have a dental plan, you may qualify for vacuform mouth guards (used for cancer patients undergoing chemo & radiation.) They are used at night (with Biotene) to protect your teeth from dry mouth.
- * More info to follow in future articles!

Optometrist or Eve specialist

A) Treatment, especially interferon, can affect your eyes. Many of these changes resolve themselves within 6 months post treatment, but should you have any lasting effects or concerns, the examination will give your doctors a baseline to work with.

Immunizations

- A) Immunity is lower during treatment and your doctor will likely advise you to get a flu shot. This should not cost anything in BC, as we qualify as "higher risk."
- B) If you have not already had your Hep A & B shot (also free for us), please discuss this with your health care professional.

Supplements

List all vitamins, minerals and supplements you are currently taking (or likely to take), and show them to your primary Hep C, Health Care professional.

Multivitamin

- A) Our reserves can get low while on treatment. A multivitamin can help.
- B) Ask your health care professional if your multivitamin should include iron.

Vitamin B12

- A) Anemia is a common side effect of treatment. Vitamin B12 is used in the body to help build healthy blood cells.
- B) Some studies have shown that those who take Vitamin B12 during treatment are even more likely to clear the virus.

Vitamin D3

- A) Some studies have shown that those who take Vitamin D3 during treatment are even more likely to clear the virus.
- B) Available in drops, chewable tablets or pill form.

Over the Counter Medications

Ibuprofen (Advil)

A) For treating fever, pain and inflamma-

tion.

Acetaminophen (Tylenol)

A) For fever and pain.

Dimenhydrinate (Gravol)

- A) For treating nausea.
- B) The pharmacist often has larger bottles behind the counter, highly recommended!
- C) Gravol suppositories. A small box is good to have on hand. If you have a day where you can't keep your food down, it can help you to take your medications on time.
- D) Can cause drowsiness.

Loratadine (Claritan)

A) This antihistamine won't make you drowsy. Helpful with sinus congestion as it promotes drainage.

Diphenhydramine (Benadryl)

- A) Helpful during treatment for treating minor skin reactions. * For strong skin reactions, contact your health care professional immediately.
- B) Can cause drowsiness.
- C) Not recommended (unless with doctors consent) for those under 6 or over 60.

Loperamide (Imodium)

- A) For treating diarrhea.
- B) Often 1/2 a tablet is enough to get things back on track.

Probiotics

- A) Available in health food stores.
- B) Probiotics can help with digestion, diarrhea and fungal infections (yeast etc.).
- C) Probiotics can counter the affects of antibiotics and should not be used in conjunction without first discussing with your health care professional.

Eye drops

- A) Eyes can become dry during treatment.
- B) Lubricating eye drops, or artificial tears can help reduce the irritation due to dryness.

Rubbing alcohol & antibiotic ointment (Polysporin)

- A) On treatment, our white blood cell count can become low making it difficult for our bodies to fight infection. Small scratches that would normally heal in a day or two can linger, increasing the risk of infection.
- B) Clean any scratches thoroughly with soap and warm water then sterilize and apply the antibiotic ointment.

Rhinaris

A) Nasal Mist. Great for moisturizing the sinuses.

Biotene

- A) Used to treat symptoms of dry mouth. Comes as a toothpaste, gel or mouthwash.
- B) Many dentists offer sample packs for

free. This is a great way to try the product or have it on hand should you develop this symptom.

Over the Counter Supplies

Scent Free, Delicate Laundry soap

- A) The skin can become very sensitive during treatment. Double rinsing your clothes and using a scent free, delicate laundry soap can go a long ways towards managing this.
- B) Consider not using a fabric softener during treatment as the chemicals and perfumes may irritate the skin.
- C) If you are prone to allergies or have sensitive skin, consider pre-washing all your clothes, towels and bedding with the scent free soap, and double rinsing before treatment begins.

Soap, Shampoo & Conditioner

- A) Purchase delicate shampoos, soaps and conditioners to help prevent skin irritation.
- B) Nioxin has a line of hair products beneficial to those on treatment.

Flushable baby wipes

A) For use after bowel movements to help treat and prevent soreness. Especially helpful if you are taking Telaprevir (Incivek).

Diaper rash ointment

A) For prevention and treatment of irritation of the anal area.

Tissues

- A) To help clear the sinuses.
- B) Have a box handy in your bedroom, washroom and other living areas of the house.

Lip Balm

A) To treat and prevent chapped lips.

Sunscreen

A) Treatment can make your skin more sensitive to direct sunlight.

Extra Soft Toothbrushes

- A) Treatment can cause your mouth and gums to become tender. Using an extra soft toothbrush can help minimize the irritation brushing can induce.
- B) If your gums bleed while brushing, consider changing your tooth brush weekly until your viral count drops to undetectable. This may help you to prevent re-introducing the virus into your system.

Disposable Razors

- A) Start treatment with a new razor.
- B) Do not use the same razor for more than a few days until your viral count drops to zero. This can help you to prevent reintroducing the virus into your system.
- C) Ladies: If your white blood cell count is low, consider not shaving, or shaving only on the weeks when your white blood cell count

 $(Continued\ on\ page\ 6)$



Victoria, December 1st, 2013

BEST OF THE UPCOMING FESTIVE SEASON TO ALL!

The holiday season gives us time to reflect on activities of the past year, savour our successes, and plan an even better future. Along with our warmest wishes, we would like to share with you some of HepCBC's many achievements and challenges, and request your continued support in 2014.

For over 10 years, HepCBC has consistently provided crucial support and information to the hepatitis C community. **This last year, we've faced drastically reduced funding, forcing us to close our downtown office**. Because both the hepatitis C and broader communities recognize the high quality of our primarily volunteer-run, client-focused services, we are confident that ways will be found to continue offering them somehow. However, even operating at our current downsizing, our accountant warns that <u>HepCBC's bank account will be empty within a year or so. Without additional support, we will soon be forced to suspend hard-copy publishing and mailings, limit services, and become 100% volunteer-run. Here is what we do now:</u>

EDUCATION and OUTREACH

We have continued to publish the *hepc.bull*, Canada's leading hepatitis C newsletter, every month since March, 1996. Our website (<u>www.hepcbc.ca</u>), pamphlet series, and FAQ's provide relevant, up-to-date information for people infected or affected by hepatitis C - in both official languages and Spanish. We are working with UVic students to develop a program to inform local teens about hepatitis C risk factors.

SUPPORT

HepCBC's Victoria office was our nerve centre, a safe place to meet, and home to our resource library, and we hope to re-open it as soon as our finances permit. We regularly receive requests for information and support from all over North America and beyond, and still provide phone, email, or in-person peer support to anyone affected by this disease. Monthly peer support meetings are held in a friendly, informative, confidential setting.

AWARENESS and PUBLICITY

HepCBC works at local, provincial, federal, and international levels to combat ignorance and stigma about hepatitis C. Besides cooperating with local agencies, we actively participate in national and international hepatitis C organizations which inform decision-makers about hepatitis C needs, best-practices and current research.

ALLISON CROWE'S "TIDINGS CONCERT" - DECEMBER 7, 2013

HepCBC announces the return of Allison Crowe's popular "Tidings Concert" to benefit HepCBC and Artemis Place. Don't miss this exciting seasonal concert on December 7 (8:00 pm) at the Fairfield United Church. For tickets, please contact Anamaria at 250-595-3892 or anama.hepcbc@gmail.com

TAX-DEDUCTIBLE DONATION: Your tax-deductible contribution will go directly to hepatitis C education, awareness and support. **Thank you for giving generously.**

I want to help HepCBC! **Please mail your cheque and the form below to:** P.O Box 46009, 2642 QUADRA ST, VICTORIA BC V8T 5G7

HepCBC Hepatitis C Education and Prevention Society is a Registered Canadian Charity: 86800-4979-RR0001

As a volunteer (we'll forward you infor	mation)		
Here is my tax-deductible donation of	\$30	\$50	\$100	Othe
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ALLISON CROWE'S VICTORIA TIDINGS

Saturday, December 7, 2013 Fairfield United Church 1303 Fairfield Road, Victoria, BC, Canada V8S 1E3

Music 8:00 pm

(Doors 7 pm)
Good Parking Available
To aid Artemis Place
www.artemisplace.org/
(Girls' educational and life-skills),
and HepCBC
www.hepcbc.ca

Tickets now online at www.allisoncrowe.com/shoptickets.html
Tickets will also be available at physical outlets.

Listen to Allison:
www.youtube.com/watch?
y=vIMOdVXAPJ0

L/F SHORTBREAD COOKIES

- 2 C powdered sugar,
- 4 C flour
- ½ t baking powder
- ₹ ½ t vanilla
 - ½ t salt
- 2 sticks softened salted butter
- 8 oz low fat softened cream cheese

Sift dry ingredients into a bowl. In another bowl, blend butter and cream cheese till fluffy. Add sugar slowly to mix well. Blend in vanilla. Add flour slowly. Mix to form a ball. Flatten dough down to an inch. Wrap in wax paper, and chill for 30 min. Preheat oven to 350. Grease or spray cookie sheet. Roll dough down to 1/4 to 1/2". Cut with cookie cutter. Bake 7-10 min. until bottom is slightly golden. Makes 75.

General tips for healthier cookies: Replace about one-third of flour with white whole wheat flour, reduce butter by a third, using cream cheese as a substitute.

(**TREATMENT TIPS**—Continued from page 4) is higher.

D) Men: If your white blood cell count is low, consider growing a beard or using an electric razor, sanitizing it with alcohol and allowing to fully dry between uses.

Trident Extra Care

- A) A sugar free gum that strengthens tooth enamel, good for dry mouth.
- B) Recommended max usage: 2 pieces, 4x a day.

Moisturizing Cream

- A) Look for a good, scent free moisturizer as your skin can become dry during treatment
- B) Unscented Glysomed and Aveeno are among the many brands that work well.

Coconut Oil

- A) Coconut oil from the grocery store is amazing for treating dry skin and cracked fingers.
- B) Rub into the skin, and dab with a tissue to remove excess residue.

Micropore Tape

- A) Available in the first aid section of the pharmacy. It is inexpensive and works wonders for cracked fingers.
- B) Apply a small piece over the cracked finger. (No need to wrap around the full digit). It helps by creating a washable barrier between the wound and everything you touch.

Bandages

- A) Purchase small, circular bandages (preferably ones that breath well) to apply to injection sites.
- B) Remove the next day as bandages can increase heat on the skin and cause irritations, especially for those experiencing rashes.

Liquid meal replacement (Ensure, Boost)

- A) Ideal to use when your stomach is upset, medications are due and you need to eat.
- B) To replace or supplement a meal.
- C) TIP: I used it to replace food for my nocturnal medications. It made life much easier!

Ginger ale & Soda Crackers

A) For nausea and upset stomach.

Freezable Gel packs

A) Gel packs help with rashes by offering immediate relief, drawing out heat and discouraging growth.

BPA Free Water Bottles

- A) During treatment, you need to drink approx. 8 glasses of water a day.
- B) TIP: I found that having 2 water bottles in the refrigerator and 1 on the go worked really well.
- C) TIP: I like to have a plastic, sippy cup style container by my bed. It works wonder-

fully as you can take a sips in the dark without the risk of spillage.

Coffe

- A) Some studies have shown that drinking at least 3 cups of coffee a day can improve the chances of SVR, while other articles recommend avoiding caffeine.
- B) Personally, my stomach wasn't able to handle coffee on treatment, I wasn't used to it and my body rejected the idea.
- C) Research the topic, talk to your doctor and decide for yourself. If you already drink coffee, this may be the one bonus of being on treatment, permission to enjoy more than one cup!

Pillow Cases

- A) To help reduce hair loss while on treatment, it is important to use a pillow case that causes as little friction as possible.
- B) Options can include: Hemp, silk or extra fine linen

Apps

A) If you have an ipod, ipad, iphone or android phone, consider downloading an app that records the medications you have taken. Many are available for free, have alarms and can help you keep track of the medications you have (and haven't) taken.

I wish you the best of luck on your treatment! You have the opportunity to fight Hep C with the very latest and best medications available. Take care of yourself, get plenty of rest, ask questions, accept help when offered and rejoice in the knowledge, you are not alone.

Sandy J. was diagnosed in 1997 with type Hep C, Genotype 1a. She completed 28 weeks of triple therapy: Ribavirin, Victrelis & Interferon in July 2013. 3 months post treatment, she is undetectable.

THANKS!!

HepCBC thanks the following institutions and individuals for their generosity: The late John Crooks, Allison Crowe, Billie Wood and Adrian, Community Living Victoria, Victoria Positive Living Centre, Provincial Employees Community Services Fund, the Victoria Foundation, Dr. C. D. Mazoff, Lorie FitzGerald, Judith Fry, and the newsletter team: Beverly Atlas, Diana Ludgate, Alp, Cheryl, Anamaria, S.J. and L.P.

Please patronize these businesses that have helped us: Top Shelf Bookkeeping, Merck Canada, Roche Canada, Vertex, Gilead, Janssen, Bristol-Myers Squibb, Boerhinger-Ingelheim, VanCity, Shoppers Drug Mart, Market on Yates, Country Grocer, Safeway and Thrifty Foods.

SVR HONOUR ROLL

We often hear only the stories of those who are suffering with Hep C. Our responders go back to "real life" and want to forget about their struggles with Hep C. Have you responded to treatment and remained undetectable for a minimum of 12 weeks* after finishing treatment (i.e., SVR or Sustained Viral Responder)? Let us help you celebrate. You can give others hope. Please take a minute and send us your name, genotype, date of SVR, and type of treatment to post here, and we'll add your name (or initials). Congratulations to our friends:

- 1. **GJ** Dec 1998 IFN/RBV 52 wks—Dr Anderson /Natalie Rock , Vancouver, BC.
- 2. **Amberose** 2000 GT 2A/2C Schering IFN/RBV 24 wks
- 3. **Jeanie Villeneuve -** Oct 2000 -Schering IFN/RBV
- 4. Kirk Leavesley (GT1) 2004 Roche
- 5. **Darlene Morrow** (GT1 relapser) Mar 2004 -Hyperthermia/Induction + pegIFN/RBV.
- 6. **Beverly Atlas** (GT1a) 2006 Albuferon/RBV 44 wks
- 7. **Steve Farmer** 2008 (Transplant Vancouver 2005) IFN/RBV 72 weeks.
- 8. **Gloria Adams** (GT1b relapser) Fall 2009 IFN/RBV/Telaprevir 48 wks -Drs Erb & Yoshida, Vancouver, BC.
- 9. **Don Crocock** (GT1) Stage II Dec. 2010 IFN/RBV 48 weeks
- 10. **Daryl Luster** (GT1a) Feb 2011 IFN/RBV/RO5024048 48 wks.
- 11. **Donna Krause** (GT1 partial responder) SVR -Nov 2011– Pegasys/Copegus, Danoprevir/Ritonavir/R05024048 24 wks Dr. Erb, Vancouver.
- 12. **Cheryl Reitz** (GT1b partial responder) SVR12 Mar 2013 Asunaprevir/Daclatasvir 24 wks Dr. Ghesquierre, Victoria, BC.
- 13. **Anita Thompson** (GT1a treated 3 times) Cirrhosis April 2013 Pegasys/Boceprevir 48 wks. Dr. M. Silverman, Whitby, ON.
- 14. **Leon Anderson** (GT2 partial responder) SVR24 May 8, 2013 GS-7977/RBV 16 weeks Dr. Alenezi & Dr. Conway- VIDC Vancouver.
- 15. **Joan King** (GT1b treated 5 times) SVR24 June 2013 Asunaprevir/Daclatasvir 24 wks Dr. Ramji, Vancouver, BC
- 16. **Sandy J.** (GT 1a treatment naïve) SVR12 Oct 31, 2013 IFN/RBV/Victrellis 28 wks. Fran Faulkner, RN, Vancouver Island. [**NEW ADDITION**]

We know there are many more of you. Please send your name and information to Joan at info@hepcbc.ca and help raise the hope of those still infected.



CONFERENCES

HEP DART 2013 frontiers in drug development for viral hepatitis 8-12 Dec 2013

The Fairmont Orchid -Big Island, Hawaii www.informedhorizons.com/hepdart2013/

3rd Global Workshop on HCV Therapy Advances New Antivirals in Clinical Practice 13-14 December 2013 Rome, Italy (t.b.c.) www.virology-education.com/index.cfm/

2013 International Conference on Viral Hepatitis 24-25 December 2013 Bangkok, Thailand

www.waset.org/conferences/2013/bangkok/icvh/

7th Paris Hepatitis Conference 13-14 January 2014 Paris, France www.aphc.info/home.php

AGA Clinical Congress of Gastroenterology and Hepatology 2014 17-18 Jan 2013Miami FL www.gastro.org/education-meetings/educationmeetings-v2

German Association for the Study of the Liver 30th Annual Meeting 2014 24-25 Jan 2014 Tubingen, Germany www.medical.theconferencewebsite.com/ conference-info/GASL-2014

> Stockholm Liver Week 2014 5-7 Feb 2014 Stockholm, Sweden www.leverveckan.se/en

3rd Canadian Symposium on Hep C Virus CAHN; CDDW & CASL 7-11 Feb 2014 Toronto, ON, Canada www.livernurses.org/cahn-2014 www.cag-acg.org/cddw

EASL - The International Liver Congress 2014 Wednesday, 9-13 April 2014 International Convention Centre ExCeL London, United Kingdom www.easl.eu

INCIVEK CARE

Vertex's Incivek Care Patient Assistance Program supports patients with the reimbursement process for Incivek (telaprevir) treatment (Incivek, pegIFN, ribavirin). It will give you an efficient assessment of your options and eligibility. You may qualify to receive co-payment and other financial assistance to supplement your private and provincial drug program coverage. The program also provides dispensing and home delivery options, and expert treatment advice. Call the Support Line at 1-877-574-4298. (Select option 2 for English, then 2 for Incivek Care.)

MERCK CARETM

MerckCare[™] is a program to help people who have been prescribed PEGETRON[™], VICTRELIS[™] or VICTRELIS TRIPLE[™]. The program provides:

- assistance with reimbursement and/or insurance claims.
- financial assistance for co-pay, deductible for people who qualify.
- 24/7 nursing support by phone.
- multilingual assistance.
- home delivery of medication.

MerckCareTM provides all of these services free of charge.

To enroll in MerckCare™, you can call 1-866-872-5773 or your doctor or nurse can submit an enrollment form for you. Reimbursement specialists are available from 8:00 a.m. to 8:00 p.m. EST Monday to Friday, excluding statutory holidays.

PEGASSIST

The PegAssist Reimbursement Assistance Program provides reimbursement coordination assistance for patients who have been prescribed Pegasys or Pegasys RBV. The program will assist in securing funding for patients to ensure that they can start, stay on, and complete their treatment successfully. PegAssist Reimbursement Specialists are available (Monday to Friday, 10 AM - 6 PM EST) by calling: 1-877-PEGASYS or 1-877-734-2797. Patients can also obtain a program enrollment form from their nurse/physician to gain access to the program.

The program provides financial aid to qualified patients, alleviating financial barriers which may prevent patients from starting treatment, i.e., deductibles and/or copayments. In partnership with CALEA Pharmacy, the program can conveniently deliver the medication directly to patients' homes or to the clinics.

NEUPOGEN VICTORY PROGRAM

Amgen has a program for patients who have been prescribed Neupogen. A reimbursement assessment is conducted by a specialist who will help you navigate through your personal or provincial coverage options. Dependent on specific criteria, some patients may be able to obtain Neupogen on a compassionate basis free of charge. Please note that Amgen will only provide Neupogen to patients on a compassionate basis as long as it is prescribed and dosed in accordance with the approved product monograph. This service is accessed through the Victory Program: 1-888-706-4717.

COMPENSATION

LAW FIRMS

1986-1990

Bruce Lemer and Company Vancouver, BC Phone: 1-604-609-6699 Fax: 1-604-609-6688

www.lawyers-bc.com/classactions/clalawy.htm

Pre-1986/Post-1990

red-cross.php

Klein Lyons Vancouver, BC 1-604-874-7171, 1-800-468-4466, Fax 1-604-874-7180 www.kleinlyons.com/class/settled/hepc/

Lauzon Belanger S.E.N.C. (Quebec) Toronto, ON Phone 416-362-1989; Fax 416-362-6204 http://lblavocats.ca/en/class-actions/hepatitis-c/active/

Kolthammer Batchelor & Laidlaw LLP #208, 11062 – 156 Street, Edmonton, AB T5P-4M8 Tel: 780-489-5003 Fax: 780-486-2107 http://www.kbllaw.com/

LOOKBACK/TRACEBACK

Canadian Blood Services Lookback/Traceback & Info Line: 1-888-462-4056

Lookback Programs, Canada: 1-800-668-2866

Canadian Blood Services, Vancouver, BC 1-888-332-5663 (local 3467) or 604-707-3467

Lookback Programs, BC: 1-888-770-4800

Hema-Quebec Lookback/Traceback & Info Line: 1-888-666-4362

Manitoba Traceback: 1-866-357-0196

Canadian Blood Services, Ontario 1-800-701-7803 ext 4480 (Irene) <u>Irene.dines@Blood.ca</u>

RCMP Blood Probe Task Force TIPS Hotline

1-888-530-1111 or 1-905-953-7388 Mon-Fri 7 AM-10 PM EST 345 Harry Walker Parkway, South Newmarket, ON L3Y 8P6 Fax: 1-905-953-7747

CLASS ACTION/ COMPENSATION

Class Action Suit Hotline: 1-800-229-5323 ext. 8296 Health Canada Compensation Line: 1-888-780-1111 Red Cross Compensation pre-86/post-90 Registration: 1-888-840-5764 <u>HepatitisC@kpmg.ca</u>

Ontario Compensation: 1-877-222-4977 Quebec Compensation: 1-888-840-5764

CLAIMS ADMINISTRATOR

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1986-1990

Administrator 1-877- 434-0944 <u>www.hepc8690.com</u> <u>info@hepc8690.com</u>

Pre-86/Post-90

Administrator 1-866-334-3361 preposthepc@crawco.ca www.pre86post90settlement.ca

Settlement Agreement:

www.pre86post90settlement.ca/PDFs/SA/

SUPPORT BC/YUKON

Armstrong HepCURE Phone support 1-888-437-

AIDS Vancouver Island The following groups provide info, harm reduction, support, education and more: • Campbell River: Drop in, needle exchange, advocacy. 1371 C - Cedar St. leanne.cunningham@avi.org 250-830-0787

• Comox Valley Harm reduction, counselling, advocacy. 355 6th St., Courtenay. Contact Sarah sarah.sullivan@avi.org 250-338-7400

• Nanaimo Counseling, advocacy. 201-55 Victoria Rd Contact Anita for details. 250-753-2437 anital.rosewall@avi.org

• Port Hardy (Port McNeil, Alert Bay, Port Hardy, Sayward, Sointula and Woss) Drop-in kitchen. 7070 Shorncliffe Rd. Contact Tom, 250-949-0432 tom.fenton@avi.org.

• Victoria Access Health Centre, drop in, disability applications, peer training. Support group Tues 12:30 PM, 713 Johnson St., 3rd floor, 250-384-2366 Hermione.jefferis@avi.org

Boundary HCV Support and Education Contact Ken 250-442-1280 ksthomson@direct.ca

Burnaby HCV Support Contact Beverly 604-435-3717 batlas@telus.net

Castlegar Contact Robin 250-365-6137 eor@shaw.ca

Chilliwack PCRS Hep C Prevention, peer support, harm reduction. Meetings 3rd Mon monthly, 45904 Victoria Avenue, Chilliwack . Contact Kim Lloyd 604-798-1416. lbirdsall@pcrs.ca www.pcrs.ca

Comox Valley Positive Wellness North Island Treatment/Pre & Post-treatment Support Group 2nd & 4th Wed., 615-10th St, Courte-River Community Health, 3rd Floor-5000 nav. Lunch. Contact Chervl

Cheryl.taylor@viha.ca 250-331-8524.

CoolAid Community Health Centre, Victoria. Meetings each Wed 10 AM and Thu 1:30 PM. 713 Johnson St. Support for all stages of treatment (deciding, during, after). Contact Roz rmilne@coolaid.org for treatment or group info.

Courtenay HCV Peer Support and Education. Contact Del 250-703-0231 dggrimstad@shaw.ca

Cowichan Valley HCV Support Contact Leah 250-748-3432 *r-l-attig@shaw.ca*

HepCBC info@hepcbc.ca, www.hepcbc.ca

• Victoria Peer Support: 4th Tues. monthly 7-8:30 PM, Victoria Health Unit, 1947 Cook St. Contact 250-595-3892 Phone support 9 AM-10 PM. 250-595-

•Fraser Valley Support/Info: 604-576-2022

Kamloops ASK Wellness Centre. Chronic illness health navigation/support.

info@askwellness.ca 250-376-7558 1-800-661-7541 ext 232 or Merritt health housing & counseling 250-315-0098

www.askwellness.ca

Kamloops Hep C support group, 2nd and 4th Wed monthly, 10-1 PM, Interior Indian Friendship Society, 125 Palm St. Kamloops. Contact Cherri 250-376-1296 Fax 250-376-2275

Kelowna Hepkop: Phone support, meeting info. Contact Lisa 1-866-637-5144 limortell@shaw.ca

Mid Island Hepatitis C Society Contact midislandhepc@hotmail.com

Nanaimo Hepatitis C Support Meetings 1st & 3rd Thu 3-5 PM 437 Wesley St. (access off Franklyn St) Contact 250-585-3201, <u>hepctxpeersupport@hotmail.com</u>

Nelson Info & support for prevention, testing, treatment and living well with hepatitis C. Women's gathering monthly. Contact Laura 1-800-421-2437, 250-505-5506, ankorshepc@ankors.bc.ca

New Westminster Stride "HepC" Support Group each Fri 10 AM except 4th Fri. of the month. Nurse Practitioner, refreshments. Contact: Stride Workers 604-526-2522, mail@purposesociety.org

Positive Wellness North Island-North Island Liver Service Info, support, treatment. Doctor or self-referral. 1-877-215-7005 250-850-2605

•Courteney: 2nd Fri monthly 1PM, Drop-in, Comox Valley Nursing Centre (nurse)
• Campbell River: 2nd Tues monthly 1PM

Drop-in, Salvation Army Lighthouse. (nurse)

Penticton & District Community Resources Society, Harm Reduction Program, Meetings every 2nd Tues, 12:30-1:30 PM. 330 Ellis Street. Contact Melanie: 250-488-1376 or 250-1 hepccommcoord@gmail.com, 492-5814

Positive Haven Info, harm reduction, support, drop in, clinic. 10697 135A St. Surrey. Contact Monika 604-589-9004.

Positive Living Fraser Valley (Abbotsford) Hep C support, Drop-in centre NEW: #108-32883 S. Fraser Way, M-F 10:30 AM-4:30PM. Info, support worker, rides to appointments in surrounding areas. Contact 604-854-1101 or plfvcentre@plfv.org

Ave. Contact Melinda Melinda.herceg@vch.ca 604-485-3310

Prince George Hep C Support Contact Ilse ilse.kuepper@northernhealth.ca

Queen Charlotte Islands/Haida Gwaii & Northern BC support. Contact Wendy 250-557-2487, 1-888-557-2487. http://health.groups.yahoo.com/group/ <u>Network-BC</u>/ wendy@wendyswellness.ca www.wendyswellness.ca

Sunshine Coast-Sechelt Healthy Livers Support Group Information/resources, contact Catriona 604-886-5613

catriona.hardwick@vch.ca or Brent, 604-740-9042 <u>brent.fitzsimmons@vch.ca</u>

VANDU The Vancouver Area Network of Drug Users. 380 E Hastings St. M-F 10-4 Contact 604-683-6061

<u>vandu@vandu.org</u> <u>www.vandu.org</u>

Vancouver Hepatitis C Support Group Contact 604-454-1347 or 778-898-7211, or call 604-522-1714 (Shelley), 604-454-1347 (Terry), to talk or meet for coffee.

Vernon telephone buddy, M-F 10-6 Contact Peter, pvanbo@gmail.com Tel. 250-309-1358.

YouthCO HIV/Hep C Society of BC. Drop-in T&W 12-3, Fri. 9-12. Call for appts M-F 10-6. 205-568 Seymour St, Vancouver 604-688-1441, 1-855-YOUTHCO Stewart stewartc@youthco.org, Briony brionym@youthco.org www.youthco.org

Whitehorse, Yukon-Blood Ties Four Directions Contact 867-633-2437 1-877-333-2437 bloodties@klondiker.com



OTHER PROVINCES

ONTARIO:

Contact Jeanie for info/ appointment

jeanievilleneuve@hotmail.com

Hamilton Hepatitis C Sup**port Group** 1st Thurs. monthly, 6-7 PM, Hamilton Urban Core Community Health Centre, 71 Rebecca St. Hamilton. Contact Maciej Kowalski, Health Promoter 905-522-3233 <u>mkow-</u> alski@hucchc.com

Hep C Team, AIDS Committee of North Bay & Area. Education, outreach, treatment, individual & group support, harm reduction, needle exchange, 269 Main St. W. Suite 201, North Bay. Contact 705-497-3560, 1-800-387-3701 or www.aidsnorthbay.com

Hepatitis C Network of Windsor & Essex County
Last Thurs. monthly, 7 PM, Teen Health Centre-Street Health Program Office, 711 Pelissier St., Suite 4, Windsor. Contact Andrea Monkman 519 -967-0490 or hepcnetwork@gmail.com. http://hepcnetwork.net

Kingston Hep C Info HIV/ AIDS Regional Service. Contact 613-545-3698, 1-800-565www.hars.ca hars@kingston.net

Kitchener Area Support 3rd Wed. monthly, 7:30 PM, Ray of Hope Community Room. 659 King St. East (Enter off King St) Kitchener. Contact Bob 519-886-5706, Mavis of NS. Info and support line 519-743-1922 or waterlooregionhepcsupport@gmail.com

London Hepatitis Hep C Support 186 King St, London. For those infected as well as affected by Hep C. Contact: 519-434-1601, 1-866-920-1601,

www.hivaidsconnection.com

Niagara Region Hepatitis C Care Clinic Education, Counseling and Support - Individual / Group, Treatment, Community Outreach, harm reduction. Contact 905-378-4647 ext 32554

HCCC@niagarahealth.on.ca www.niagarahealth.on.ca/ services/hepatitis-c-care

Oshawa Community Health Centre Hepatitis C Team Drop-in, lunch provided each Thurs. 12-1 PM, 79 McMillan St. www.ochc.ca Contact 1-855-808-6242

Owen Sound Info, support. Contact Debby Minielly dminielly@publichealthgreybruce.on.c

<u>a</u> 1-800-263-3456 Ext. 1257. Barrie Hepatitis Support 519-376-9420, Ext. 1257, www.publichealthgreybruce.on .ca/

> Peel Region (Brampton, Mississauga, Caledon) 905-799-7700

healthline-

peel@peelregion.ca

St. Catharines Contact Joe 905-682-6194

Toronto CLF 1st Mon. monthly Oct.-June, 7:30 PM, North York Civic Centre, 5100 Yonge Street. Contact Billie 416-491-3353, ext. 4932.

bpotkonjak@liver.ca www.liver.ca

Thunder Bay Hep C support. Contact Sarah Tycholiz 807-345-1516 (or for 807 area only 1-800-488-5840)

Unified Networkers **Drug Users Nationally** undun@sympatico.ca

York Region Hepatitis C Education Group 3rd Wed. monthly, 7:30 PM, York Region Health Services, 4261 Hwy 7 East, B6-9, Unionville. Contact 905-940-1333, 1-800-361-5653 info@hepcyorkregion.org www.hepcyorkregion.org

OUEBEC:

Quebec City Region Contact Renée Daurio 418-836-

reneedaurio@hotmail.com

ATLANTIC PROVINCES

of NS. Info and support line for the entire province. Call 1-800-521-0572, 902-420-1767

Online Peer Support: <u>info@hepns.ca</u> www.hepns.ca

PRAIRIE PROVINCES:

Manitoba Hepatitis phone and email support and outreach. Info Line: 1-204-779-6464 or contact Kirk at info@mbhepc.org. Direct line: 1-204-389-5814

Medicine Hat, AB Hep C Support Group 1st & 3rd Wed. monthly, 6:30 PM, HIV/ AIDS Network of S.E AB Assoc, 550 Allowance Ave. Contact 403-527-7099 bettyc2@hivnetwork.ca



To list Canadian groups here, please send details to <u>info@hepcbc.ca</u> by the 15th of the month. It's free!