

## Canada's Hepatitis C News Bulletin

www.hepcbc.ca

#### FINAL EDITION!

## FINAL EDITION OF THE hepc.bull

To Our Readers: It is with many mixed feelings that we are announcing Issue #200 to be the last print edition of the hepc.bull. Now you can get the latest news from HepCBC at <a href="https://www.hepcbc.ca">www.hepcbc.ca</a>, on Facebook at <a href="https://www.facebook.com/hepcbc">www.facebook.com/hepcbc</a>, and Twitter at <a href="https://www.twitter.com/hepcbc">www.twitter.com/hepcbc</a>

What's more, you won't have to wait a month to get the latest news, since we update our sites daily, as the news comes in.

For those who are now getting the hard copy of the bulletin but don't have access to the Internet, we offer to photocopy a selection of the most popular articles and blog entries of the previous month, once a month and mail them to you. Please contact us if this is the case.

# PATIENT INPUT REQUESTED BY BC PHARMACARE FOR GILEAD'S EPCLUSA®

Hello! Once again, HepCBC is calling for your input. BC PharmaCare is reviewing whether to add another Direct Acting-Antiviral (DAA) for hepatitis C to its formulary (list of drugs it will cover).

Patient and caregiver input is requested by BC PharmaCare on Gilead's combo of sofosbuvir and velpatasvir for genotypes 1-6 (brand name: Epclusa®). Gilead's combo is the first pan-genotypic (works for all genotypes) treatment which PharmaCare is considering for coverage. The combo, which generally achieves a 95% or better cure rate, was approved by the FDA (in the US) in June, 2016, and received a notice of compliance (NOC) from Health Canada on July 11, 2016.

Because Epclusa® works on all strains of the virus, it eliminates the need for genotype testing, which can be difficult to access, especially for those living in rural or remote regions of the country—and can delay treatment.

If you would like to participate in this drug review, go to <a href="http://wp.me/p7rc49-2E1">http://wp.me/p7rc49-2E1</a> and follow the directions. HepCBC will put all the responses together and submit them to BC PharmaCare as part of our group opinion as to whether we think this combination of drugs should be recommended as a hepatitis C treatment.

DEADLINE FOR SUBMISSION TO HepCBC is MIDNIGHT,

Sunday, September 18, 2016

#### FIBROSIS IN HCV GENOTYPE 3 PROGRESSES WITH AGE

According to data presented at the British Society of Gastroenterology Annual Meeting, evidence of fibrosis was common in older patients with hepatitis C virus genotype 3 infection, indicating fibrosis progresses with age and that this patient population should be treated as often and with the same medications as other severely-affected HCV patient populations. <a href="https://goo.gl/Rxyp34">http://goo.gl/Rxyp34</a>

#### DAA'S AND LIVER CANCER

Data from 2 studies presented at EASL 2016 indicate that patients infected with hepatitis C virus (HCV) who were treated with direct-acting antiviral (DAA) therapy were more likely to experience *a recurrence* of hepatocellular carcinoma (HCC) than those who had no previous history of the disease. http://goo.gl/vMr9Mz

Another study highlighted that although DAAs prove to be effective in the majority of patients, they do not appear to reduce the risk of HCC, at least in the short term, – especially in those with a history of the condition. http://goo.gl/6HbP6N

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## TAINTED BLOOD HEARING RESULTS!

*3 LOCATIONS, 1 CASE:* From June 20–22, 2016, hearings were held concerning the Canadian government's request to "claw back" (or appropriate) an estimated \$250 million "surplus" from the "1986-1990" Tainted Blood hepatitis C victim-compensation fund. HepCBC and others gathered in Vancouver to watch the live hearings (held in Toronto) in courtroom #52, between 8:30 and 2:30 each day.

2 FUNDS, 2 CLASSES: HepCBC equally supports all victims of the tainted blood scandal (no matter in which year they contracted HCV); there is also a "Pre-86/Post-90" compensation fund, which is largely depleted and unable to compensate its victims properly. We publicly demonstrated our support for all victims at both the opening and closing of the hearings outside the Vancouver courthouse, getting local TV coverage on the final day.



HepCBC members in front of Vancouver Courthouse, June 22, 2016

THE ARGUMENTS: Government lawyers contended that the "excess" money belongs to all the people of Canada, and hence should revert to the government. Victims' lawyers contended the surplus should be allocated to "1986-1990" Class Members, for whom it was intended; Class Members' needs change over the years as their disease

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#### IN MEMORIUM: LORETTA "LORIE" FITZGERALD



\*Loretta "Lorie" Fitzgerald (1938 – June 10, 2016):

Lorie passed away peacefully on June 10, 2016. Born in 1938 in Saskatoon to Myrtle and Palmer Pederson where her big brother Donnie (Donald), "brat"

as she affectionately called him, was waiting for her. The Pederson's moved to Brantford, Ontario where they raised their children. Lorie was involved in scouting and was Akela for the local cubs. She started babysitting at age 9 and working for Woolworths at 14. As she grew, Lorie loved fishing, dancing on weekends, and going to Hamilton to watch her Tiger-cats play. After high school graduation she went on to nurses training at Brantford General Hospital where she graduated in 1959.

After a vacation in Victoria, BC, Lorie fell in love with the west coast. She made it her permanent home in 1961. Lorie's effervescent personality won her many friends and dates but, it was through her first job at St. Joseph's hospital that she met her future husband David Shaw Fitzgerald. They were married in 1962 and were together for 43 years until his death in 2006. They had 3 daughters whom they raised in Victoria.

Lorie worked in various areas throughout her 40+ years of nursing. She was highly respected and admired by the staff and patients who had the privilege of knowing her. Her career gave her many lifelong friendships both in Brantford and Victoria. Lorie enjoyed curling, playing bridge and coaching girls softball. She also enjoyed the simple pleasures in life such as afternoon tea, drives along Victoria's water front, ice cream cones from the Beacon Drive-In, feeding the ducks at Beacon Hill Park and summer days swimming at Elk Lake. Lorie was on the board of directors of HepCBC, along with her husband, for many years. They helped to raise awareness of HepC and provided hope and support to many.

She leaves behind her daughters Debbie, Shawna, and MarLynn. She also leaves behind her son's in law, Marcus, Jon and Quinn., her grandchildren, Tanner, Dakota, Kiera (Cortez), Spencer, Shelby, and Jackson, and her great grand-daughter, Annelise. More details can be found here: <a href="http://sandsfuneralvictoria.sharingmemories.ca/site/Loretta-FitzGerald.html?s=40">http://sandsfuneralvictoria.sharingmemories.ca/site/Loretta-FitzGerald.html?s=40</a>

## THE SQUEEKY WHEEL

In a recent article about hepatitis C and chronic kidney disease, Dr. Annette Bruchfeld MD, PhD reminded me of this very important truth:

"Chronic HCV infection should be seen as a metabolic disease that causes chronic systemic inflammation through direct viral effects on the vasculature and indirect effects via the immune system and the liver. The result is a proinflammatory state that increases the risk of atherosclerosis, cardiovascular disease, the metabolic syndrome, and diabetes." <a href="http://goo.gl/z6lNjx">http://goo.gl/z6lNjx</a>

As long as we continue to think of HCV as primarily a liver disease, then we will feel comfortable waiting until the liver tells us that it is sick. But as we all know, doctors and scientists from all around the world have shown clearly that the dangers and costs of not treating HCV as early as possible are enormous.

Increasingly nations and states are removing restrictions to treatment, such as waiting for liver damage to occur, and financial deterrents. Australia, France, Brazil, the Republic of Georgia, Egypt and Taiwan have made the decision to treat all their citizens and to cover the costs. In the USA, the Veterans Administration will now treat all in its system without restriction, and several states, such as Massachusetts, Washington, Pennsylvania, Delaware, California. Colorado and Florida have eased or removed restrictions to Medicare for treating HCV. Meanwhile, in Canada: In BC only 1500 people a year get treated via PharmaCare. We get many calls to HepCBC from people desperately seeking treatment who have been denied PharmaCare because their liver damage is not sufficient, and who cannot afford treatment. Do we tell people with diabetes to wait until we amputate something or until they go blind until we treat? The attitude is, frankly, unconscionable. The bottom line is the buck and not the citizen. Big boo!

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#### MEETING AT BC HEALTH MINISTRY ABOUT HE AND ESLD

On August 23, 2016 HepCBC and one of BC's leading hepatologists presented on "UNMET NEEDS OF BC'S CRITICAL PATIENTS WITH HEPATIC ENCEPHALOPATHY (HE) AND END STAGE LIVER DISEASE (ESLD)" at the BC Ministry of Health to the Chief of Staff, Martyn Lafrance. Two volunteer advocates, a patient and a caregiver, were accompanied by gastroenterologist Dr. Alnoor Ramii.



Cheryl Reitz, Dr. Alnoor Ramji, and Susan Malloch

Our goals were to show the anguish of both having and giving care to those suffering from HE, to document the financial burden of HE and ESLD on the people and the Province of BC, and to show some ways that the personal anguish and the public costs could be alleviated

We had 30 minutes, and we think we did a good job! We are hoping BC PharmaCare will soon cover HE drug rifaximin, used for many years throughout the world as an alternative for those who cannot tolerate lactulose, or in combination with it.

Canada has recently approved rifaximin, and it is now covered by all provinces' PharmaCares except for BC's. To view and download the slideshow HepCBC presented to Lafrance, "Understanding Hepatic Encephalopathy: Examining the effects of HE on patients in British Columbia," see <a href="http://goo.gl/xZ7q3g">http://goo.gl/xZ7q3g</a>).

## **HepCBC OFFICES**

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VICTORIA (MAIN) OFFICE, #20- 1139 Yates Street: Tuesdays & Thursdays 1 pm5:30 pm, Wednesdays 11 am-5:00 pm, Fridays 12 pm-2 pm, OR other times by appointment (call or email to arrange).

### VANCOUVER (OUTREACH) OFFICE,

#206A-938 Howe Street. Mondays and Thursdays, 9:30 am-2:30 pm OR other times by appointment (call or email to arrange).

SUPPORT PHONE LINE NUMBERS: VANCOUVER & LOWER MAINLAND:

1-604-259-0501

**THE REST OF BC**: 1-778-655-8000

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(TAINTED BLOOD HEARINGS—Continued from page 1) progresses, and due to circumstances beyond their control many Members were unable to fill out their Application Forms properly or on time, disqualifying them from deserved compensation. As well, lawyers representing Members of the "Pre-86/Post-90" fund were working behind the scenes, trying to get both the government and the "1986-1990" Class Members to consider the inequity their Class Members are experiencing, hoping some of the "excess" could be allocated to top off their Class Members' dwindling

THE UNDIAGNOSED: Also at issue is the fact that many new victims still have not been diagnosed. This action may set a precedent that could affect eligible victims of both the funds, as well as the many people who could potentially enter either of the classes but are not yet diagnosed, or did not apply before the deadlines. Proposed broader testing of Baby Boomers could feasibly locate many more. Cheryl Reitz, from HepCBC testified on behalf of undiagnosed victims who do not yet know they are Class Members; her testimony can be read here: http://hepcbc.ca/2016/06/21/cheryl-reitzs-verbatimtestimony-todays-blood-scandal-compensation-fundhearing/.

3 DECISIONS: The "1986-1990" fund is the result of three Class Actions on behalf of Class Members who contracted HCV between 1986 and 1990: the Ontario Action represents all Class Members in Canada except those in BC and Quebec. The first Class Action was BC's, and Quebec's followed. So there were three judges and three separate Decisions which you can read at: http://www.hepc8690.ca/ home-e.shtml

THE RESULTS: In short, the "1986-1990" Class won! All three judges agreed the "excess" money should go to meet their further needs, and ways are now being formulated to determine individual Class Members' needs equitably. The government lost its case. The compelling needs of the "Pre-86/Post-90" Class Members were not addressed at this time. though the case brought new attention to their plight

#### THANKS!!

HepCBC thanks the following institutions and individuals for their generosity: The late John Crooks, Allison Crowe, Provincial Employees Community Services Fund, the Victoria Foundation, Dr. C.D. Mazoff, Judith Fry, and the newsletter team: Beverly Atlas, Alp, Cheryl, Anamaria, and S.J.

Please patronize these businesses that have helped us: Top Shelf Bookkeeping, Merck Canada, Bristol-Myers Squibb, Roche Canada, Vertex, Gilead, J Boehringer-Ingelheim, AbbVie, Janssen, Rx&D, VanCity, Lupin, and Thrifty Foods.

To Right: Dr. Carole Williams, MP Murray Rankin, and HepCBC advocacy volunteer Cynthia Carter

The three judges mentioned this inequitable situation several times during the hearings, lamenting that a re-allocation of at least some of the surplus to these victims was not possible given the legal circumstances. This decision further increases the disparity between the two Classes. It appears that \$30 - 40 million is still unallocated: victims and their lawyers are hopeful at some point the Govt. of Canada will re-allocate these funds to "Pre-86/Post-90" Class Members.

**NOTE:** there will be a hearing in December, 2016 for the "Pre-86/Post-90" Settlement Fund compensation fund to the PELD fund.

#### **MORE INFO:**

- "1986-1990": Lise Carmichael of CFM Lawyers in Toronto at lcarmichael@cfmlawyers.ca or http://www.hepc8690.ca/home-e.shtml
- Lawyers in Vancouver and Ottawa at lporteor http://www.pre86post90settlement.ca/.
- Both classes: http://www.hemophilia.ca/en. hcv-hiv/hepatitis-c-and-hiv-compensation/.

#### TOWN HALL MEETING ADVOCACY RE: BABY BOOMER SCREENING

On August 25, 2016 HepCBC Advocacy Volunteer Cynthia Carter attended a Town Hall "Seniors' Roundtable" event sponsored by Victoria MP Murray Rankin (NDP). The main speaker, representing the Canadian Medical Association (CMA), was Dr. Carole Williams. Cynthia asked Dr. Williams whether the association would support the recommendation for one-time HCV screening of all Canadians born between 1945 and 1975, made by the Canadian Liver Foundation and the Canadian Association for the Study of the Liver. Unfortunately her answer was not supportive of this idea. We urge everyone to ask doctors and politicians about this recommendation, just to let them know it has been made, and to get them thinking about the issue.



#### FOOD INSECURITY RISK **FACTORS AMONG HIV-HCV** CO-INFECTED HIGHER THAN LIVING WITH HIV OR HCV

Of the roughly 250,000-plus Canadians with chronic hepatitis C virus (HCV) about 10,000 of them also have human immunodeficiency virus (HIV). People living with both HIV and HCV have specific health concerns and, in some cases, unique social circumstances.

A new study (published in AIDS Behav. 2016 Feb 24) examining risk factors for food insecurity among on the reallocation of a small portion of the main HIV-HCV co-infected people gathered information about food insecurity from the larger CTN 222 Canadian HIV/HCV co-infection cohort (www.cocostudy.ca). By collecting food insecurity information along with demographic, economic, and health data, researchers were able to identify possible risk factors for food inse-

"Among 525 study participants, 59% experienced "Pre-86/Post-90": Lisa Porteous of Klein food insecurity," said Taylor McLinden, one of the researchers working on CTN 264. "Risk factors for ous@callkleinlawyers.com (604-714-6533) food insecurity included: recent injection drug use and recent experiences of depressive symptoms." The study also found that trading food for things like tobacco, household items, or drugs was associated with food insecurity, highlighting increased financial difficulties and competing needs for resources in this population.

> Food insecurity is a term used to describe a situation of limited or uncertain access to nutritious and safe food. About 8% of Canadian adults can be categorized as food insecure. Food insecurity negatively affects a person's health and well-being and may be a result of a number of factors, including: housing insecurity, addictions, unemployment, and poor social support.

> Because people living with both HIV and HCV have specific health concerns, previous studies looking at food insecurity may not be generalizable to this population. This gap in understanding led to CTN 264 in 2012. The study was undertaken by Drs. Joseph Cox and Anne-Marie Hamelin of McGill University and is funded by the Canadian Institutes of Health Research and the CIHR Canadian HIV Trials Network (CTN).

> By identifying risk factors, interventions to limit food insecurity in people with HIV-HCV can be further developed. Inclusion of food support as a part of harm reduction programs and mental health services are two potential areas of future study.

> Using the data collected from this study, the researchers will also explore how certain risk factors impact food insecurity, how food insecurity negatively impacts health, and how food insecurity differs in people living with HIV-HCV across Canada.

> Reference: "Food Insecurity in HIV-Hepatitis C Virus Co-infected Individuals in Canada: The Importance of Co-morbidities," Cox J. et al. AIDS Behav. 2016 Feb 24. [Epub ahead of print] http://goo.gl/

> Sean Sinden, Communications & Knowledge Translation Officer CIHR Canadian HIV Trials Network <u>ssinden@hivnet.ubc.ca</u>

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## ACTION HEPATITIS CANADA WHITE PAPERS POWERFUL TOOLS FOR ADVOCACY

Action Hepatitis Canada has some wellresearched position statements you can refer to in your advocacy and press releases. Each contains impressive references backing up positions on:

- Age Cohort (born 1945 1975) Testing
   http://www.actionhepatitiscanada.ca/
   uploads/8/3/3/9/83398604/
   ahc\_position\_paper\_ age\_cohort\_testing.pdf
- Access to Treatment (Lowering Fibrosis -Level Criteria)

http://www.actionhepatitiscanada.ca/
uploads/8/3/3/9/83398604/
ahc\_position\_paper\_access to treatment.pdf

• Pricing of Treatment

http://www.actionhepatitiscanada.ca/ uploads/8/3/3/9/83398604/ ahc position paper - pricing.pdf



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There are alternatives however: If you are not incapacitated by your HCV and have some savings and are prepared to travel, you can always get treated in India (hepc.bull, Jan., 2016), or even Egypt. Another great alternative is to register for the Redemption eTrials, where you can be cured for around \$2000 CDN. There is some red tape and running around with this option, though—some due to the nature of clinical trials, and some due to certain restrictions that our federal and provincial governments impose—but which you can work around. If you decide that you want to enroll in the Redemption eTrial. (http://goo.gl/BOFPdX), contact us at HepCBC and we will provide you with a roadmap!



## ELIMINATING HCV AT THE COMMUNITY LEVEL: REALISTIC OR A DREAM?

The Cherokee Nation, one of the largest Native American tribes, has been the first community in the US to set a goal of eliminating HCV from its population. Tribe officials plan to screen 300,000 members, whose prevalence of infection for the virus is five times the national rate, and treat them with drugs that have proven 90 percent effective.

Check out this great video: <a href="https://www.youtube.com/watch?">https://www.youtube.com/watch?</a>
v=94RLcsVo7OU&spfreload=10

Over HALF of the infected tribal members are younger than 50, so now everyone over age 20 who comes into the Cherokee health system will automatically be tested for hepatitis C.



#### VIRAL HEPATITIS 'KILLS AS MANY AS AIDS OR TB'

Viral hepatitis is one of the leading killers across the globe, with a death toll that matches AIDS or tuberculosis, research in *The Lancet* suggests.

The report estimates that hepatitis infections and their complications led to 1.45m deaths in 2013 – despite the existence of vaccines and treatments.

World Health Organization data shows there were 1.2m AIDS-related deaths in 2014, while TB led to 1.5m deaths.

The WHO has put forward a global strategy to tackle hepatitis.

- Source Article: <u>The global burden of viral</u> <u>hepatitis from 1990 to 2013: findings from</u> <u>the Global Burden of Disease Study 2013</u>
- Read more here: <a href="http://www.bbc.com/news/health-36717828">http://www.bbc.com/news/health-36717828</a>

For the record: Canada has signed on to the Global Strategy on Viral Hepatitis at the World Health Assembly in Geneva, Switzerland. The goal – the elimination of hepatitis B and C by 2030 – signals the greatest ever global commitment on viral hepatitis. Read more about this at <a href="http://hepcbc.ca/2016/06/16/canada-takes-stand-viral-hepatitis/">http://hepcbc.ca/2016/06/16/canada-takes-stand-viral-hepatitis/</a>. Our federal government, has not yet indicated how or when it will begin to address the ongoing burden of viral hepatitis in Canada.

## NOT GETTING THE MESSAGE: TOO MANY BOOMERS UNAWARE OF THEIR STATUS

The Canadian Liver Foundation says levels of awareness and testing for hepatitis C are dangerously low among Canadians born between 1945-1975, and urges those at risk to get tested. In fact a recent survey showed over 80 per cent of Canadians in this age bracket are unaware of their increased risk, and only one quarter have been tested. http://goo.gl/UXJIS5

While the human costs of the disease are significant, the projected financial impact is also troubling. A report published in the *Canadian Journal of Gastroenterology and Hepatology* in May 2014 estimates that health care costs associated with the disease will increase 60 per cent by 2032, as untreated or undiagnosed patients age and their liver diseases progress.

The unfortunate reality is that no matter how many times advocates' and physicians' organizations have urged the federal government of Canada to implement a national strategy, we have heard little except that PHAC "has determined that further analysis is required." Somebody please shoot me!

Meanwhile in Alberta, internationally-recognized virologists Dr. Michael Houghton and Dr. Lorne Tyrrell, both based at the University of Alberta, said that Alberta should look at spending \$134 million on a hepatitis C screening and treatment program for the province's baby boomers, most of whom are unaware they carry a heightened risk of infection.

Tyrrell said he and Houghton would ultimately like to see a federally-coordinated effort around hepatitis C rather than have individual provinces continue to attack the problem in different ways. He said Canada could learn from the approaches of other jurisdictions such as the United States, Scotland and Australia, the last of which recently announced a \$1-billion investment toward the cost of drugs.

In the meantime, Tyrrell said Alberta can make a good start by screening and treating its baby boomers for an estimated \$134 million. A more robust program that includes other high-risk groups would cost about \$253 million.

Currently, Blue Cross and drug insurers are covering drug costs only for patients with some sign of advanced liver disease, Tyrrell said. He said he and Houghton would like to see coverage extended to those at earlier stages to help prevent the virus from being spread.

Work led by Houghton at the U of A is closing in on the world's first vaccine against all seven genotypes of the hepatitis C virus. Phase one clinical trials are scheduled to begin next year. <a href="http://goo.gl/HCYtGz">http://goo.gl/HCYtGz</a>

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## TREATMENT DIMINISHES PORTAL VEIN HYPERTENSION

A research group led by hepatologists Mattias Mandorfer and Karin Kozbial of MedUni Vienna's Department of Gastroenterology and Hepatology have now demonstrated that portal vein hypertension also diminishes once the hepatitis C viral infection is healed. This is a relief for patients, because it means they can stop taking drugs with unpleasant side-effects and they do not need to undergo stressful check-ups quite as frequently.

Although the hepatitis C virus can no longer be detected in people who have recovered, it was previously not known how reversible cirrhosis and portal vein hypertension, in particular, are. This is an important issue, because portal hypertension can result in bleeding from varicose veins in the oesophagus or the development of ascites or abdominal

Mattias Mandorfer: "As a general rule, the probability of portal vein hypertension diminishing is greater, the earlier treatment was started. However, despite the promising results, we still strongly recommend that patients attend for check-ups, because portal vein hypertension does not diminish in all patients and, irrespective of whether it does or does not, there is a risk of developing liver cancer as a result of cirrhosis." http://goo.gl/ *KJWsuG* 

## Peppermint Patti's FAQs, V 10.1 !!

Do you have questions about Hep C or about treatment? Do you want to know how to make healthier choices for your liver?

> **Download for FREE:** http://wp.me/P7rc49-1T7



Yes! This issue contains the kitchen sink!

#### **OUESTIONS ABOUT** TAINTED-BLOOD COMPENSATION?

You can find your answers here:

http://goo.gl/3CBiOy

The information in this newsletter is published in good faith, for general information purposes only. We do not make any warranties about the completeness, reliability and accuracy of this information, and it is not medical advice. We try to document our sources, but cannot guarantee their accuracy. Any action you take is strictly at your own risk. HepCBC will not be liable for any losses and damages in connection with use of the information provided.

#### SVR HONOUR ROLL

Have you been undetectable for at least 2014.) Sofosbuvir/ledipasvir + RBV 24 wks. 12 weeks after treatment? Encourage others. Add your name! Congratulations to our SVR Jan 2014 - PegIFN/RBV +boceprevir friends: Online: http://hepcbc.ca/svr-honour-roll/

1. GJ - SVR Dec 1998 - IFN/RBV 52 wks., Dr. Anderson / Natalie Rock, Vancouver, BC.

2. **Jeanie Villeneuve** - Oct 2000 - Schering IFN

IFN/RBV 24 wks.

4. KG-Transfused 1987 (treatment-naïve GT2A/2C) IFN/ RBV 24 wks., 2003-2004, Toronto. SVR confirmed IFN/RBV/Victrelis, Dr. S. Wong, WHSC.

5.Murray Palmer (GT1a) Transfused. SVR 2003 Rebetron 48 wks (cleared at 24 wks.) SVR confirmed 2010

6. Darlene Morrow (GT1 relapser) - Mar 2004 Hyperthermia/Induction + pegIFN/RBV.

7. Kirk Leavesley (GT1) - 2004 - Roche

8. Beverly Atlas (GT1a) - 2005/2006 - Albuferon/ RBV 44 wks.

9. Steve Farmer (Transplant Vancouver 2005) IFN/RBV 72 weeks. SVR 2008

10. Gloria Adams† (GT1b relapser) - Fall 2009 IFN/RBV/telaprevir 48 wks., Drs. Erb & Yoshida. Vancouver, BC)

11. Don Crocock (GT1 Stage II) - Dec. 2010 IFN/ RBV - 48 wks.

12. Daryl Luster (GT1a) - Feb 2011 - IFN/RBV/ RO5024048 48 wks.

13. **Donna Krause** (GT1 partial responder) SVR Nov 2011- Pegasys/Copegus, danoprevir/ritonavir/ R05024048 24 wks., Dr. Erb, Vancouver.

 Hermione Jefferis (GT1a) - SVR 2011 PegIFN/RBV, 48 wks., Dr. Partlow, Victoria, BC

15. Cheryl Reitz (GT1b previous partial responder) SVR12 Mar 2013 - asunaprevir/daclatasvir 24 wks. Dr. Ghesquiere, Victoria, BC.

16. Anita Thompson (GT1a treated 3 times) Cirrhosis - Apr 2013 - Pegasys/boceprevir 48 wks. Dr. M. Silverman, Whitby, ON.

Leon Anderson (GT2 partial responder) SVR24 May 8, 2013 - GS-7977/RBV 16 wks., Dr Alenezi & Dr. Conway- VIDC - Vancouver.

18. Joan King (GT1b treated 5 times) SVR24 June 2013 - asunaprevir/daclatasvir 24 wks., Dr. Ramji Vancouver, BC

19. Jackie (GT1 relapser) SVR24 June 2013 - IFN/ RBV/boceprevir 48 wks., Dr. Keith Bovell, Guelph,

20. Sandy J. (GT1a treatment-naïve) Oct 31, 2013 IFN/RBV/Victrellis 28 wks., Fran Faulkner, RN Vancouver Island. SVR24.

21. Andrew P. (GT1a many previous treatment attempts over 10+ years, including Incivek Jan

22. **Peter A Walker** (GT1a, treatment-naïve) (Eprex–for low RBC count from RBV.)

23. Diane Stoney - Transfused 3/21/79 (GT 1a treatment-naïve) Feb 4 2014 - 12 wks. placebo, then 12 wks. on ABT-450/r+ABT-267+ABT-33+RBV. Dr. Tam, Vancouver, BC

24. Coreen Kendrick (GT1a treatment-naïve) 3. Amberose (GT2a/2c) - SVR 2000 - Schering Mar 10, 2014 MK5172/MK8742 12 wks., Dr. Ramii, Vancouver, BC.

25. Jack Swartz (Treated 3 times) Apr 2014

26. Del Grimstad July 2014, 12 weeks simeprevir/Sovaldi

27. Linda May (GT1b transfused, treatmentnaïve) asunaprevir/daclatasvir 12 wks., Dr. Tam, LAIR Centre.

28. Robin Tomlin (GT1 treatment-naïve) SVR12 May 4,2014 - Harvoni 12 wks., Dr. Yoshida VGH.

29. Bob (GT1a/HIV relapser) SVR24 Nov 2014 pegIFN/RBV/Incivek 24 wks., Dr. Montaner, Salt Spring Island, BC.

30. Nancy Neel (GT1a previous relapse IFN/ RBV 48 wks.) SVR24 Mar 2015 MK-5172/MK 8742 12 wks., Dr. Ramji, Richmond, BC.

31. Catherine Luke GT3b, treatment-naïve) SVR 12 May 19,2015 SOF/pegJFN/RBV 24 wks

32. Sandra Newton (GT1a treatment-naïve, infected 1984) SVR12 Aug 2015. Harvoni 8 wks., Dr. David Pearson, Victoria, BC

33. Wendy Mackay Transfused 1971(GT1a prev. 48 wks., Victrelis Triple ) Cirrhosis, SVR24 Aug 2015, Harvoni 24 wks., Dr. Tam, LAIR Centre

34. Wendy L (GT1b pegIFN/RBV intolerant) SVR12 Sep 15, 2015, Harvoni 8 wks. Dr. Steve Brien, Peterborough ON.

35. Nancy Dunham Transplant patient. SVR 2015, Harvoni Toronto, ON.

36. Chaim David Mazoff (GT1a treated 5 times) SVR24 Mar 2, 2016 Harvoni 12 wks. Dr. Ghesquiere, Victoria, BC

37. **Judith Fry** (GT1a transfused '81,85, prev. IFN & IFN/RBV) SVR24 Apr 6 2016, Harvoni 8 wks, Dr. A. Buckley, Victoria, BC.

38. Linda Zimmerman. 7 weeks IFN/RBV in 2011. 24 weeks Harvoni in 2015.

Please send your name and info to info@hepcbc.ca

#### **HepCBC LIVER WARRIORS TEAM AT** 2016 VICTORIA MARATHON

Yes, there will be a HepCBC Liver Warriors Team again at the 2016 Goodlife FITNES Victoria Marathon! To register, go to: <a href="http://">http://</a>

www.runvictoriamarathon.com/racing-events/registration/ If you

VICTORIA MARATHON

want the Half Marathon, select "HepCBC Liver Warriors" team from the dropdown team list (if you choose a different event, you may have to type in that name in by hand.) **September 15<sup>th</sup> is** the deadline for the regular registration rate. Please let HepCBC know if you are joining this year so we can meet up with each other at the race. Hope to see you there!

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#### WHAT WE'VE BEEN UP TO THIS SUMMER!



Leslie Flamand provided testimony to Tainted Blood Hearings, demonstrated with HepCBC, and was interviewed for TV June 20-22



Visitors viewing our CARP (Cdn Assn of Retired People) info booth in Richmond June 25



HepCBC staff member John at Victoria's Tillicum Centre info booth August 6



Dr. Aida Sadr got our attention at Pos. Living BC event, WHD 2016, Vancouver, BC



Vancouver PRIDE info booth July 31



HepCBC staff members Jessie and John at Victoria's Mayfair Mall info booth June 25



HepCBC Pres., Rosemary Plummer, at CARP info booth in Richmond June 25



HepCBC Staff member Jessie and visitor at Victoria PRIDE info booth July 10



Fashionistas from Ukraine and Canada at Lookout Society, WHD 2016, Surrey, BC



Indian Music Group at WHD 2016 in Surrey



Participants gathering in front of Provincial Bldg, WHD 2016, Victoria, BC



3 MLAs listened intently with others in front of Provincial Bldg, WHD 2016, Victoria, BC



C.D. Mazoff, speaking at BC Legislature, WHD 2016, Victoria, BC



Ivan Arlantico (centre) was a temporary volunteer at our Vancouver PRIDE info booth July 31.

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#### ABBVIE CARE

With the approval of HOLKIRA PAK<sup>TM</sup>, AbbVie is launching AbbVie Care, which is a program that will provide best-in-class solutions to improve outcomes for people living with hepatitis C.

Canadians prescribed HOLKIRA PAK<sup>TM</sup> will have the opportunity to request to be enrolled in AbbVie Care. The signature care program is designed to provide a wide range of customized services including reimbursement assistance, education and ongoing disease management support. AbbVie Care will not only support health care professionals but people living with genotype 1 hepatitis C throughout their treatment journey to achieve high cure rates in the real world.

For enquiries: 1-844-471-2273.

### MERCK CARETM

MerckCare<sup>TM</sup> is a program to help people who have been prescribed PEGETRON<sup>TM</sup>, or ZEPATIER<sup>TM</sup>. The program provides:

- •assistance with reimbursement and/or insurance claims.
- •financial assistance for co-pay/
- •deductible for people who qualify.
- •multilingual assistance.
- •home delivery of medication.

MerckCare<sup>TM</sup> provides all of these services free of charge.

To enroll in MerckCare<sup>TM</sup>, 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.

### **CLAIRE**

Bristol-Myers Squibb Canada has created Claire, a patient support program designed to provide patient health information and reimbursement assistance for patients who have been prescribed DAKLINZA<sup>TM</sup> (daclatasvir). This personalized patient support program is now available, and represents a service offered at no cost to the patient and is fully confidential. It is set up so you will have a single person to take care of you during your treatment. You can call the information line for more details at: 1-844-428-2559. Should you have medical enquiries regarding DAKLINZATM, please contact our Medical Information Department at 1-866-463-6267 or email info@claireprogram.ca

#### MOMENTUM<sup>TM</sup> SUPPORT

To learn more about SOVALDI<sup>TM</sup>, HAR-VONI<sup>TM</sup> or the Momentum Program<sup>TM</sup> in Canada, the patient should speak to his/her doctor or nurse or call the Gilead Sciences Canada medical information line at 1 855 447 7977. Eligible patients may receive an integrated offering of support services for patients and healthcare providers throughout the entire treatment journey, including:

•Access to dedicated case managers/ reimbursement navigators to help patients and their providers with insurance-related needs, including identifying alternative coverage options through private, federal and provincially-insured programs.

- •The SOVALDITM/HARVONITM Co-pay assistance program, which will provide financial assistance for eligible patients who need help paying for out-of-pocket medication costs.
- Medication delivery services.
- •Compliance and adherence programs.

#### **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.

## HEALTH BENEFITS 1<sup>ST</sup> NATIONS AND INUIT

There are a number of health-related goods and services that are not insured by provinces and territories or other private insurance plans. To support First Nations people and Inuit in reaching an overall health status that is comparable with other Canadians, Health Canada's Non-Insured Health Benefits (NIHB) Program found at <a href="http://goo.gl/8K9ODK">http://goo.gl/8K9ODK</a> provides coverage for a limited range of these goods and services when they are not insured elsewhere. Their number in BC is 604-666-3331 or 1-800-317-7878 (toll-free).

#### IBAVYR<sup>TM</sup>

Pendopharm has established the IBAVYR<sup>TM</sup> Patient Support Program. The program will assist patients who have been prescribed IBAVYR<sup>TM</sup> (ribavirin tablets) with reimbursement navigation, financial assistance and pharmacy services. Case managers will support patients with insurance-related matters and assess eligibility for financial support. Pharmacy services include adherence support, medication delivery and counselling.

To enquire or to enroll, you may call 1-844-602-6858 Monday–Friday 7am to 11pm EST

### **BIOADVANCE®**

JANSSEN's GALEXOS<sup>TM</sup> (simeprevir) BioAdvance® program can assist you in many ways during your treatment. This includes compiling and submitting, on your behalf, all the forms and documents required by your insurance company to request coverage of GALEXOSTM, and following up with your insurer to get you the best coverage possible. If you don't have private insurance, the GALEXOSTM: BioAdvance® program will investigate public assistance programs that can help pay for your treatment. Whichever type of coverage you have, if your insurance does not fully cover the cost of treatment, the GALEXOSTM: BioAdvance® program can usually coordinate and provide financial assistance to help you get treated. Finally, the program can offer many other types of support and your doctor and members of your healthcare team will work with the GALEXOSTM: BioAdvance® Program to develop a customized approach to best support you throughout the course of your treatment. Contact: 1-855-512-3740.

#### CONFERENCES

**EASL - AASLD**Roadmap for Cure
23-24 September 2016

Paris, France http://goo.gl/aVGERh

3<sup>rd</sup> World Congress on Hepatitis and Liver Diseases

October 10-12, 2016 Dubai, UAE http://hepatitis.omicsgroup.com/

AASLD: The Liver Meeting November 11 - 15, 2016 Boston, MA http://goo.gl/tVEAhO

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#### SUPPORT BC/YUKON

#### OTHER PROVINCES

#### Support Groups Now Online:

http://hepcbc.ca/support/support-groups/

Armstrong HepCURE. Phone support 1-888-437-2873

AIDS Vancouver Island. The following groups provide info, harm reduction, support, education and more: • Campbell River: Positive Wellness program and counseling, harm reduction, needle exchange, advocacy. 1371 C - Cedar St.

Contact leanne.wingert@avi.org 250-830-0787

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

 Nanaimo AVI Health Centre. Counseling, advocacy. NEW: 102-55 Victoria Rd Contact Michelle for details. 250-753-2437 michelle.latour@avi.org

• Victoria Access Health Centre, Tuesday lunch, disability applications, peer training. Support group Tues 12:30-1:30 PM, 713 Johnson St., 3rd floor, 250-384-2366, ext 3112 leslie.robinson@avi.org.

#### ANKORS Hepatitis C Project

Hep C Info, support for prevention, testing, treatment and living well with Hep C.

Boundary, Nelson, West Kootenay Women's gathering monthly. 101 Baker St, Nelson. Contact Laura 1-800-421-2437 250-505-5506 ankorshepc@ankors.bc.ca

•East Kootenay 209 16th Ave N, Cranbrook, Contact Michelle 250-426-3383 1-800-421-2437 ankorshcv@gmail.com

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

Chilliwack PCRS Hep C Prevention, harm reduction. 45904 Victoria Avenue, Chilliwack. Contact Kim Lloyd 604-798-1416. <u>llbirdsall@pcrs.ca</u> <u>www.pcrs.ca</u>

Comox Valley Positive Wellness North Island Treatment/Pre & Post-treatment Support Group 2<sup>nd</sup> & 4<sup>th</sup> Wed., 615-10th St, Courtenay. Lunch. Contact Cheryl 250-331-8524. Cheryl.taylor@viha.ca

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

Haida Gwaii support. Contact Wendy wendy@wendyswellness.ca www.wendyswellness.ca

HepCBC info@hepcbc.ca, www.hepcbc.ca Call for office hours. Email support through website form. Peer phone support through:

•Lower Mainland: 1-604-259-0501 Fraser Valley Support/Info: 604-576-2022 (9 am-10 pm)

•The rest of BC: 1-778-655-8000

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,  $2^{nd}$  and  $4^{th}$  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 ljmortell@shaw.ca

Nanaimo - Central Island Hepatitis Service: Nurses & doctors available for info, support, treatment. Clinic located in Nanaimo. Doctor or self-referral. Contact 1-855-740-2607,

sarah.hughes@yiha.ca or shelby.munk@yiha.ca

New Westminster Stride with Purpose "HepC" Support Group 1<sup>st</sup> & 3<sup>rd</sup> Wed monthly 1-2:30pm Refreshments. Contact: Stride Workers

604-526-2522, mail@purposesociety.org

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

•Courtenay: 2<sup>nd</sup> Fri monthly 1PM, Drop-in, Comox Valley Nursing Centre (nurse)

•Campbell River: Treatment/pre&posttreatment support group 1st&3rd Thu monthly 10-12 noon, Discovery Room, Sunshine Wellness Centre, Campbell River Hospital. Crombie at 850-2620, Jody jody.crombie@viha.ca

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 250-492-5814

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 #108A-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 info@plfv.org

Powell River Hepatology Service Powell River Community Health, 3rd Floor-5000 Joyce Ave. Contact Melinda 604-485-3310 Melinda.herceg@ych.ca

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

Sunshine Coast-Sechelt Healthy Livers Support Group Information/resources Contact Catriona 604-886-5613 catriona.hardwick@vch.ca or Brent 604-740-9042 brent.fitzsimmons@ych.ca

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 HCV Support Contact Beverly 604 -435-3717 <u>batlas@telus.net</u>

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

Vancouver: YouthCO HIV and Hep C Society of BC. Call for appts or drop in M-F 10-6. 205 568 Seymour St, Vancouver 604-688-1441, 1-855-YOUTHCO Stewart info@youthco.org, www.youthco.org

VIDC HCV Support Group 9:30AM-12PM Every Friday 200-1200 Burrard St., Vancouver.

Contact 604-642-6429 info@vidc.ca

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

Whitehorse, Yukon-Blood Ties Four Directions Contact 867-633-2437 min@bloodties.ca

**ONTARIO:** 

Barrie Hepatitis Support Contact Jeanie for info/appointment jeanievilleneuve@hotmail.com

Hamilton Hepatitis C Support **Group** 1<sup>st</sup> Thurs. monthly, 6-7 PM, Hamilton Urban Core Community Health Centre, 71 Rebecca St. Hamilton. Contact Maciej Kowalski, Health Promoter 905 522-3233

mkowalski@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 hepccommcoord@gmail.com, 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, 1-800-565-2209 hars@kingston.net www.hars.ca

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 Health System - Hepatitis C Care Clinic (HCCC) Clinics:

New Port Centre-Port Colborne, 4 Adams Street - St Catharines, Niagara Falls Hospital. Education, counseling, individual/group support, treatment, outreach, and 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.ca 1-800-263-3456 Ext. 1257, 519-376-9420 Ext. 1257, www.publichealthgreybruce.on.ca

Peel Region (Brampton, Mississauga, Caledon) 905-799-7700 healthlinepeel@peelregion.ca

St. Catharines Contact Joe 905-682-6194

Toronto CLF "Living with Liver Disease" group 1st Mon. monthly Oct.—June, 7:30 PM, North York Civic Centre, 5100 Yonge Street. Contact Billie 416-491-3353. ext. 4932 or 1-800-563-5483 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 3<sup>rd</sup> 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 418-836-2307 reneedaurio@hotmail.com

CAPAHC support group meetings 3<sup>rd</sup> Thurs. monthly 6-8PM, 032-2065, rue Parthenais, Montreal. Contact 514-521-0444 or 1-866-522-0444

#### ATLANTIC PROVINCES

**Hepatitis Outreach Society** of NS. Info and support line for the entire province. Call 1-800-521-0572, 902-420-1767 Online Peer Support: info@hepns.ca www.hepns.ca

#### **PRAIRIE PROVINCES:**

Calgary Hep C support **group** meets 1st & 3rd Wed. monthly, 11:45am-1pm, CUPS 1001-10th Ave, SW. Contact Lynda 403-991-1930 www.cupscalgary.com lyndaw@cupscalgary.com

Manitoba Hepatitis C phone and email support and outreach. Contact Kirk at info@mbhepc.org. Direct line: 1-204-231-1437

Manitoba CLF each Thu 1:30-3. 375 York Avenue, Suite 210, Winnipeg, Contact B i a n c a 2 0 4 - 8 3 1 -6231 bpengelly@liver.ca

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 your details to info@hepcbc.ca It's free!

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