4th International HIV/Viral Hepatitis Co-Infection Meeting

The Rocky Road to Viral Hepatitis Elimination:
Assuring access to antiviral therapy for ALL co-infected patients from low to high income settings

Saturday - Sunday, 22-23 July 2017
Paris, France
Practivism

It’s the new black

Dr James Freeman with thanks to Dr Andrew Hill, Marty Two Bulls and too many other people to single out. You know who you are.
What Is Practivism?

• So what is the PR all about?
  – The PR is for Protesting Patents and Policy
  – The PR is for Public Relations
  – And the PR is for being practical, because
• The world, my friends, is as we find it and not as we might wish it to be…
• Practivism can deliver real results right now
  – Imperfect solutions for an imperfect world
Crisis, What Crisis?

The world’s medication crisis explained in under 60 seconds
5g of Diamonds

25 1-carat @ $2000 each
Cost = $50,000

5g of Daclatasvir

12 weeks @ 60mg/day
Cost = $53,000 (UK price)
Hep C Cure

ENTRY FEE
$84,000.00

Generic Hep C Cure
$1,500
YOUR MONEY
OR YOUR LIFE!
THOUSANDS OF OUR PATIENTS STILL NEED THE NEW HEP C CURE BUT HOW CAN WE CONTINUE TO PAY?
Hep C Cure Club

Sorry, I can't let you in! You're not sick enough.
Hepatitis C

1 out of every 3 Inmates are infected

Medication cost $54 to 94 thousand dollars per cure, insuring that only the sickest inmates may get treatment.
Injection opioid abuse nearly triples hepatitis C infections in 2015.

Be safe get tested
YOU HAVE JUST BEEN TRUMPED

Lower Prescription Drug Prices

Don't Lower Prescription Drug Prices

FLIP

FLOP

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GILEAD

FIRE!

Generic Cure Fix HepC
“In Germany they came first for the communists, and I didn't speak up because I wasn't a communist. Then they came for the Jews, and I didn't speak up because I wasn't a Jew. Then they came for the Catholics, and I didn't speak up because I was a Protestant. Then they came for me and by that time no one was left to speak up.”

-Rev. Martin Niemoller
‘Only when the last patient has died, the last insurer is bankrupt and pharmaceutical company profits wither will we realise that patient lives balance patent rights.’
The Law Is Not About Justice

• “The law is not about justice, the law is about the law”
  – So said the Professor of law at Sydney University in 1985
  – I was shocked, dropped out of law, and became a doctor instead

• But years later hearing those words became useful when a patient of mine needed HCV treatment and I thought…
  – “Ok, we need better laws, but what are the loopholes?”
  – “How can we go with the law, but still access treatment?”
Practivists Love Loopholes

• And fortunately TRIPS provides some flexibility
  – TRIPS Article 30 provisions a research exemption
  – TRIPS Article 31 provisions compulsory licensing
  – TRIPS Article 60 - De Minimis Imports
    “Members may exclude from the application of the above provisions small quantities of goods of a non-commercial nature contained in travellers' personal luggage or sent in small consignments.”

• These loopholes can be successfully “re-purposed”
Personal Medication Importation

• In line with Article 60 most countries allow personal medication importation
  – In many countries delivery of a 3 month supply of medication by post is entirely legal\(^1,2\)
  – In some only importation by personal carriage is allowed
• Buyers Clubs around the world facilitate this…
  – Buyers Clubs help patients navigate an unfamiliar and potentially dangerous process

1. https://www.gov.uk/government/organisations/hm-revenue-customs
2. https://www.tga.gov.au/personal-importation-scheme
Amazon

• Amazon proves it could work at scale
  – If Amazon can make a business shipping low priced items like books…

• The fundamental barrier is that medications are more expensive than books and still out of reach for the majority of patients (at least at current generic prices)
We Could Decouple The Funding

- Buyers clubs could operate at scale if funding was decoupled from the patient, but
- Personal importation rapidly rebalances monopoly negotiations\(^1\) and
- We can observe that for Australia, New Zealand, Italy and Switzerland active personal importation preceded deals with Gilead, Abbvie and Merck.
- **Was that a Coincidence or Market Forces?**

1. [http://www.thelancet.com/journals/lancet/article/PIIS0140-6736(16)32051-7/fulltext](http://www.thelancet.com/journals/lancet/article/PIIS0140-6736(16)32051-7/fulltext)
Swiss Practavists In Action

- Swissmedic changed their personal importation laws\(^1\)
- A quick regulation change, not a slow legislative change
  - From 1 month to 3 months for HCV medication import
- Swiss insurer Concordia started funding patients\(^2\)
  - Concordia decided that, while it could not directly fund generics, it could define generic HCV treatment as a reasonable medical expense and reimburse the cost…
- A group of practavists achieved that in under 1 year

1. [http://www.hepatitis-schweiz.ch/files/Dokumente/PDF/2017_Achat%20de%20medicaments%20en%20ligne.pdf](http://www.hepatitis-schweiz.ch/files/Dokumente/PDF/2017_Achat%20de%20medicaments%20en%20ligne.pdf)
2. [https://www.concordia.ch/content/dam/concordiach/de/pdf/diverses/CON_HepatitisC_Flyer_de.pdf](https://www.concordia.ch/content/dam/concordiach/de/pdf/diverses/CON_HepatitisC_Flyer_de.pdf)
Other Key Practavist Strategies

• Hep C has no funding because it has no voice
• Getting patients to speak to it is vital
• We need real inventiveness to get the message out because Big Pharma owns most of our media, doctors and politicians
• The stories “drug prices unaffordable” or “patient gets generics, gets cured” are becoming old news…
• But controversy fuels media fires so let’s be Practavists and FACT UP then ACT UP!
Life's most persistent and urgent question is, What are you doing for others?

Martin Luther King, Jr
Let’s Not Forget Our Stateswomen

“Never doubt that a small group of thoughtful, committed citizens can change the world; indeed, it's the only thing that ever has”

- Margaret Mead
A single act of caring creates an endless ripple
More Information

- http://fixhepc.com/fixers
- http://www.thelancet.com/journals/lancet/article/PIIS0140-6736(16)32051-7/fulltext
- http://onlinelibrary.wiley.com/doi/10.1111/liv.13157/full