

CREATING AWARENESS AND SHARING THE KNOWLEDGE

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International
viral hepatitis
elimination
meeting
Amsterdam
2016

DISCLOSURE OF SPEAKER INTEREST

- **No (potential) conflicts to report**

HCV IN RUSSIA – AN EPIDEMIC OF NEGLIGENCE

- Estimated 6 mln people living with Hep C (Rosпотребнадзор) = 4% of population
- Around 2 mln need treatment urgently
- PWID especially vulnerable – mid-range prevalence in dif regions 69%, up to 90%
- Treatment is currently not accessible for the vast majority of patients, no treatment for PWID

STRUCTURAL PROBLEMS

ARF 2013 STUDY

- No dedicated budget for treatment or prevention
- Gov opposed to harm reduction prms for PWUD
- No patient registry → impossible to estimate # of patients and their needs
- No HCV treatment protocols or standards
- Centralized treatment provision mostly through specialized AIDS Centers
- Low capacities of treatment facilities
- High price of the medication
- No access for PWID

LOW AWARENESS

ARF 2013 study:

I think that people don't know anything about their condition. I think many people, if not everyone, are unaware of what's going on. They don't know that treatment is available.

Patient in Togliatti, 29 yo

- Have you heard about hepatitis C treatment?
- No, I haven't. I heard it's almost incurable. You can treat it, but it's difficult, and there are few drugs available. I don't really know about it, and I have never tried to find out, to tell the truth.

Patient in Togliatti, 39 yo

ARF: raising awareness through harm reduction work and legal action



Genamum C.

**Лечение-право,
а не привилегия!**

СНИЖЕНИЕ ВРЕДА-МОСКВА

ФДАР

ФОНД ИМ. АНДРЕЯ РЫЛЬКОВА

**ГЕПАТИТ С: ЛЕЧЕНИЕ - ПРАВО.
А НЕ ПРИВИЛЕГИЯ!**

ПОМОЩЬ ОТ СЕРДЦА К СЕРДЦУ
rylkov-fond.org +7 (926) 887-90-87

**Hepatitis C – treatment
is a right,
not a privilege!**

Raising public awareness through action



HARM REDUCTION UNDERGROUND

Harm reduction work declining due to gov't opposition

- **In 2009** - 75 projects reaching out to 135.000 clients (coverage of **less than 5%** of conservatively estimated 2.5 mln PWID)
 - In 2016 - 16 projects reaching 13.800 people (**90% decrease!**) coverage = 0,5% of PWID
 - To be closed in 2017
 - Only needles and condoms are funded, no other injection equipment
- epidemiological significance of these programs for Hep C is negligible



ACCESS TO MEDICINES

- Experts say that in order to reduce incidence by 40% by 2020, at least **123.000** people should be treated annually
- ITPC analysis of state/regional purchases in 2015 indicates that only **5.000-10.000** patients may have received therapy
- 90% of them were on pegs + ribavirin
- DAAs schemes available since 2015, sofosbuvir registered in spring 2016, but not included into the LEM
- Cost of pegs remains high. The cheapest course now ~4000\$ (Algeron + ribavirin)
- Cost of DAA schemes in 2015 purchased by State/regions – around \$15K. In 2016:
 - Sofosbuvir/daclatasvir : ~ 15.500 USD
 - Sofosbuvir/simeprevir : ~ 20.000 USD

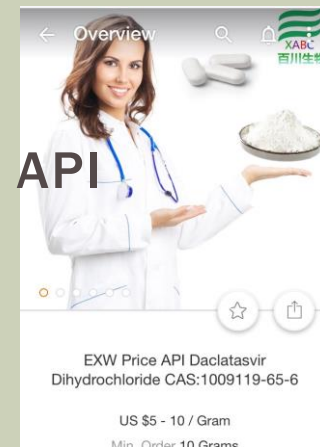
PRICE REDUCTION ACTION

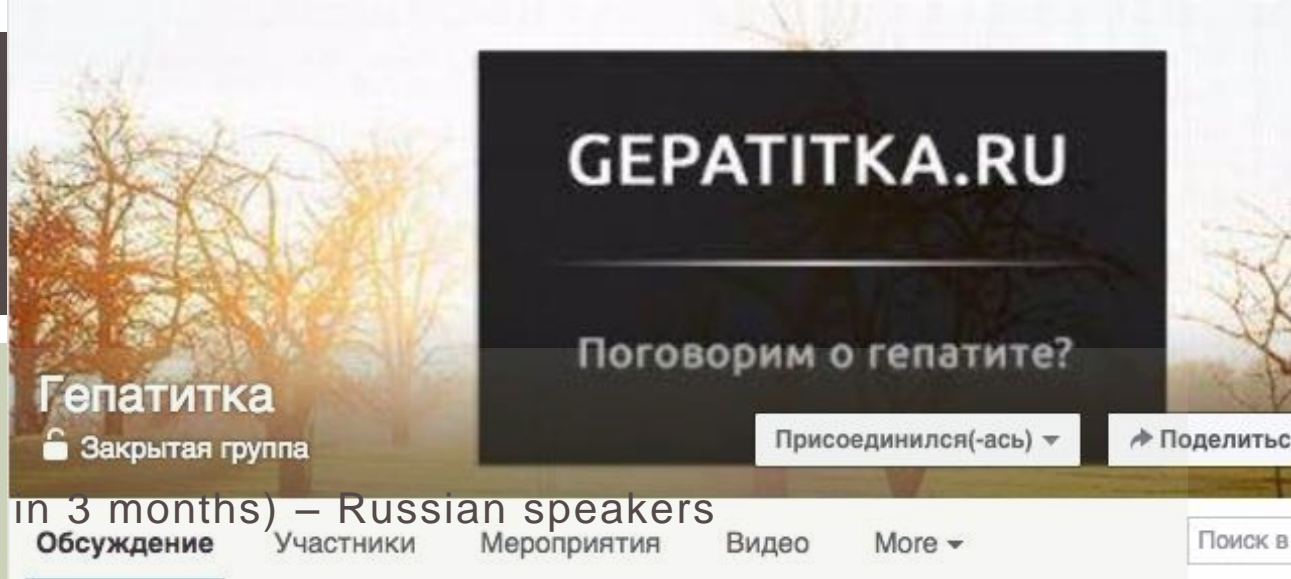
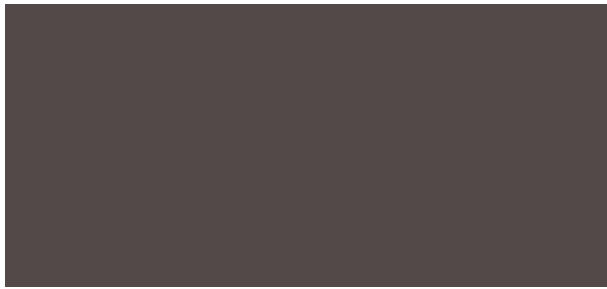
- ITPC suggests target price of 50.000 rub (770 usd)
- ITPC + Humanitarian action challenge Gilead's patent in court (dec 2016 hearing at the Patent Court)
- Putin discusses compulsory licensing of DAAs (but that's not a solution, as eg russian peg generic PegAltevir is not much cheaper than brand pegs)

PEER ACTION IN THE ERA OF NEW TECHNOLOGIES

- New technologies of meds production combined with social networking => new configurations of peer action/support
- Patient community groups (buyers clubs) – at least 3 major groups in Russia
- Self-purchase generic DAAs from India, China, Egypt
- Looking for ways to reduce prices, eg purchase powder API (dac) from China and capsule
- Self-test in labs for equivalence
- On-line counseling by doctors

⇒ Current price at +/- 30.000 rub (470\$) and going down + diagnostics (in some regions covered by insurance)





started in 2015

6100 members (+2000 in 3 months) – Russian speakers

Facebook group+

Patients conferences / education (together with ITPC)

1500-2000 received medicines though the group, only 4 people reported no SVR (anecdotal evidence)

1st study of effectiveness to be published (224 patients)

Virological Response rates using Generic Direct Acting Antiviral Treatment for Hepatitis C, Legally Imported into Russia

Andrew Hill¹; Julia Dragunova²; Roxanna Korologou-Linden³; Sergey Golovin³; Rachel Smith⁴; Vicky Houghton-Price⁴

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