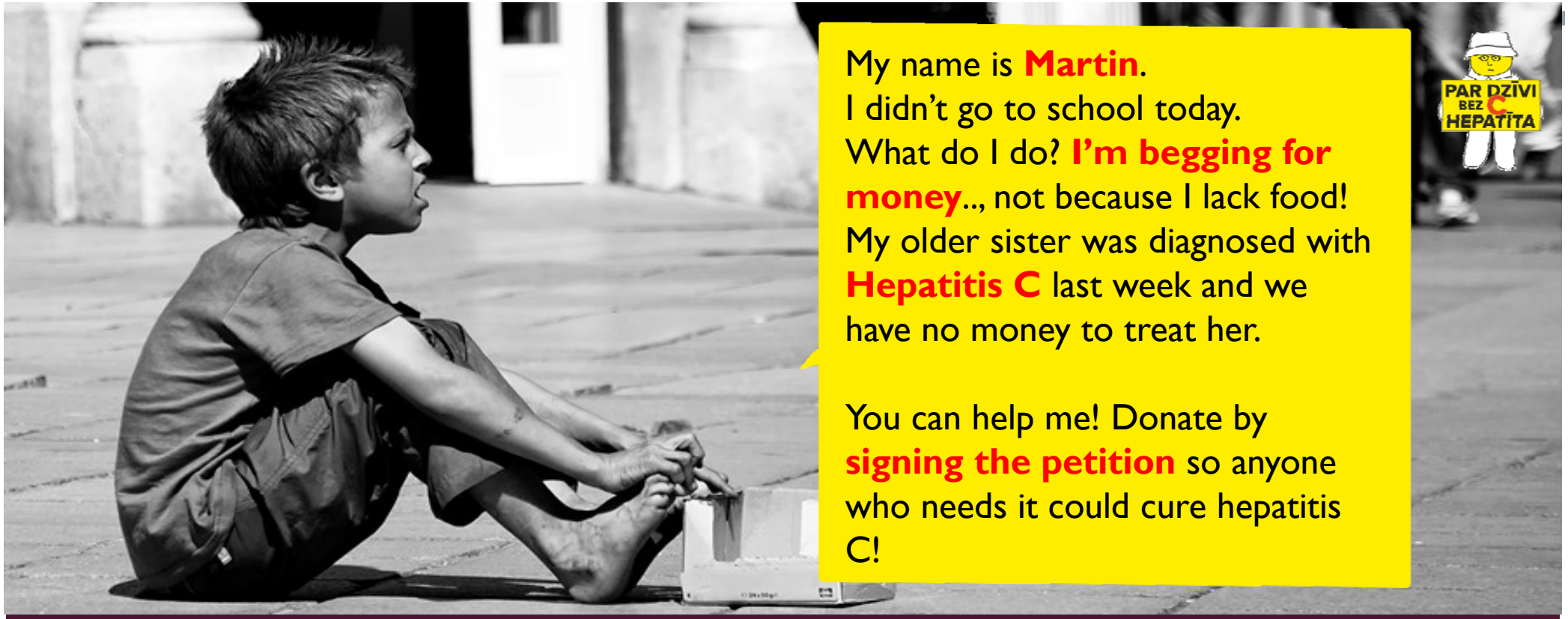
CREATING AWARENESS
FOR LIFE WITHOUT HEPATITIS C

KRISTAPS KAUGURS, HEPATITIS C PATIENTS NGO LATVIA

VIRAL HEPATITIS PREVENTION BOARD MEETING, RIGA, LATVIA, 20TH NOVEMBER 2015
PART 4.2: NGO INVOLVED IN CREATING AWARENESS FOR VIRAL HEPATITIS



CREATING AWARENESS
FOR LIFE WITHOUT HEPATITIS C

* ALTHOUGH THE CHARACTER NAMES ARE CHANGED, THE STORY IS REAL, SENT IN BY THE BOY'S SISTER.

WHO ARE WE

- HEPATITIS NGO LATVIA
- 11. years of patients right advocacy
- ¬ 250-300 registered members, 5-40 active members
- 15… 3…1 activist(s)
- Single person orchestra for many years
- Fighting for higher state compensation level (mostly)
- Manning the HELP-LINE for ¬10 years

STATE COMPENSATION LEVEL

G.Bērziņš 75%

I. Eglītis 50%

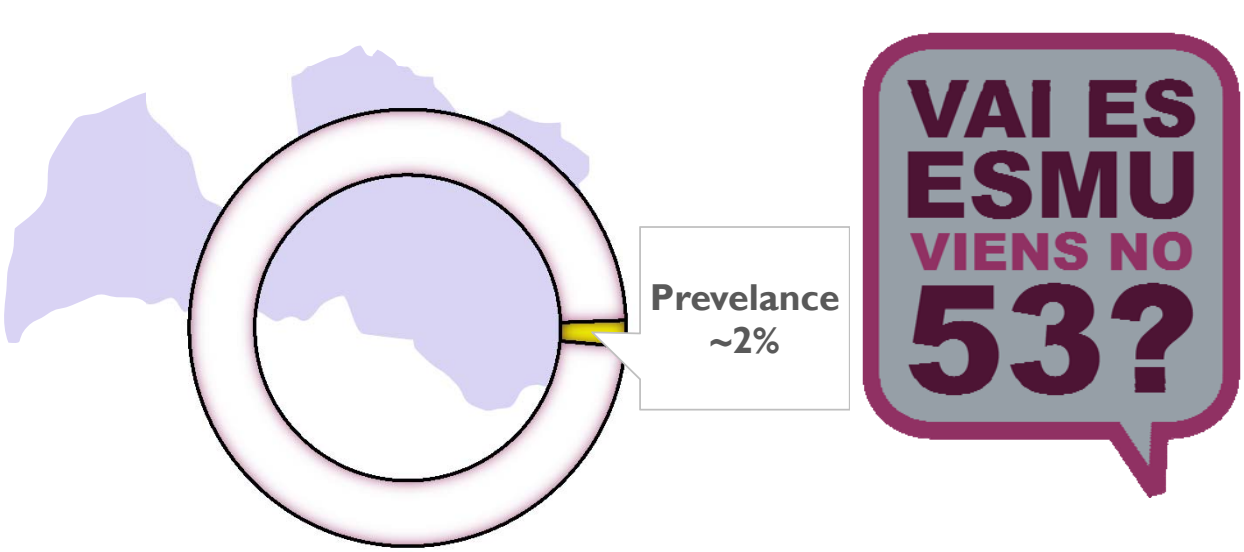
J.Bārzdiņš 75%

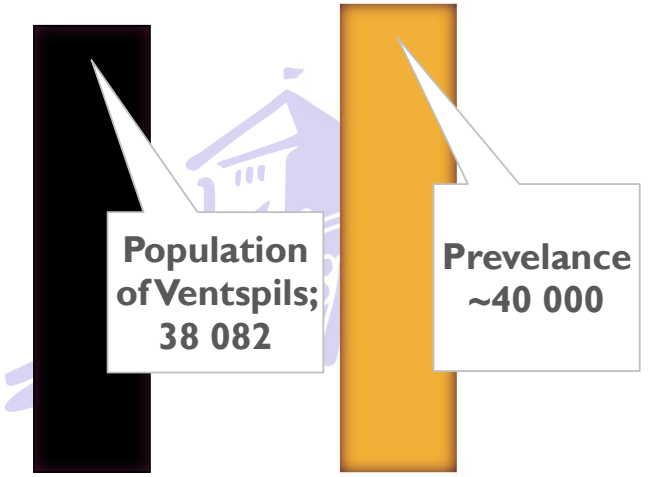
?

G.Belēvičs 100%

1990 2004 2005 2006 2007 2009 2010 2011 2012 2013 2014 2015 2016

STATISTICS

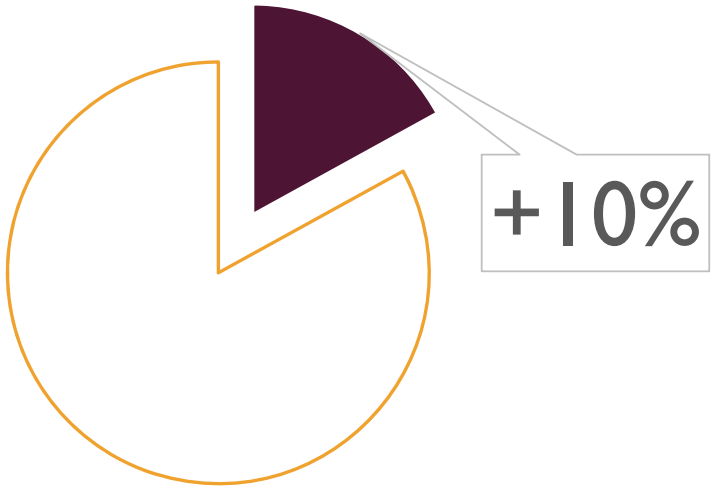




Slimību profilakses un kontroles centrs un LR Centrālā statistikas pārvalde

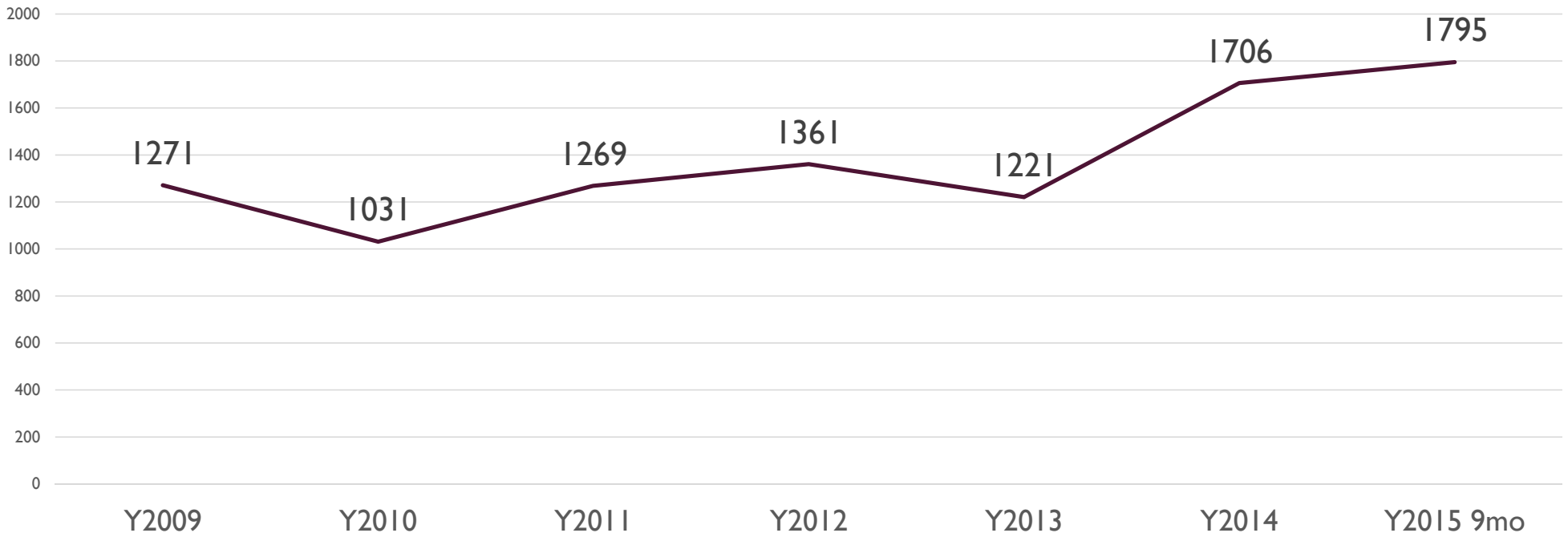
STATISTICS

New infections



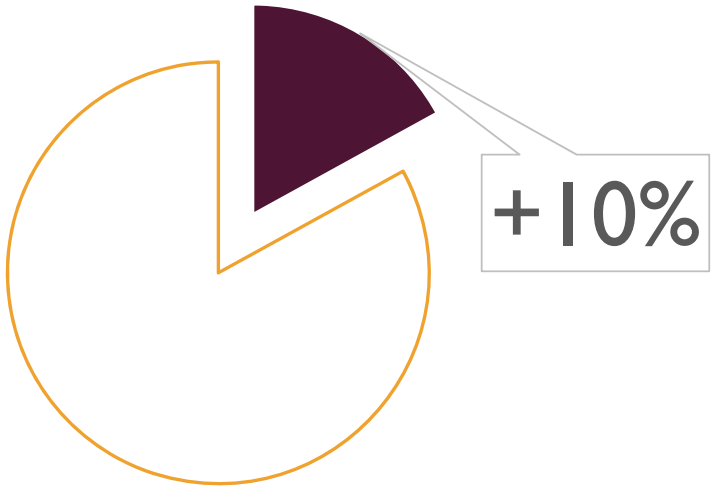
- **+10%** (2015 VS 2014 9 months)

STATISTICS: YES, IT'S A TENDENCY!



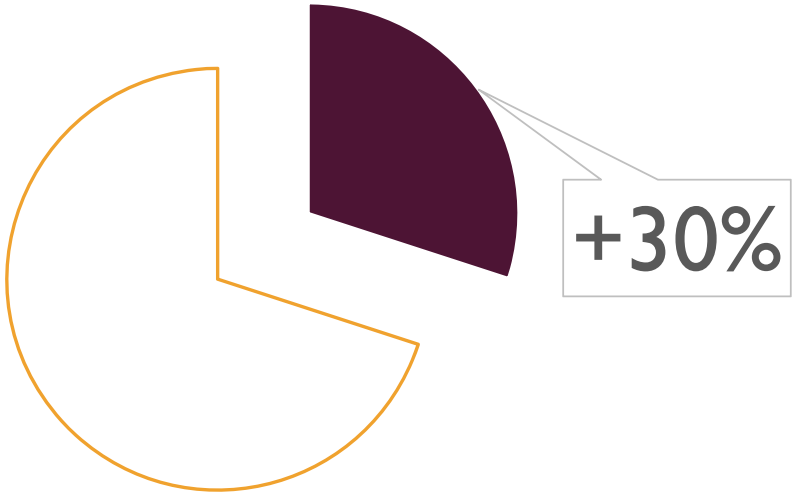
STATISTICS

New infections



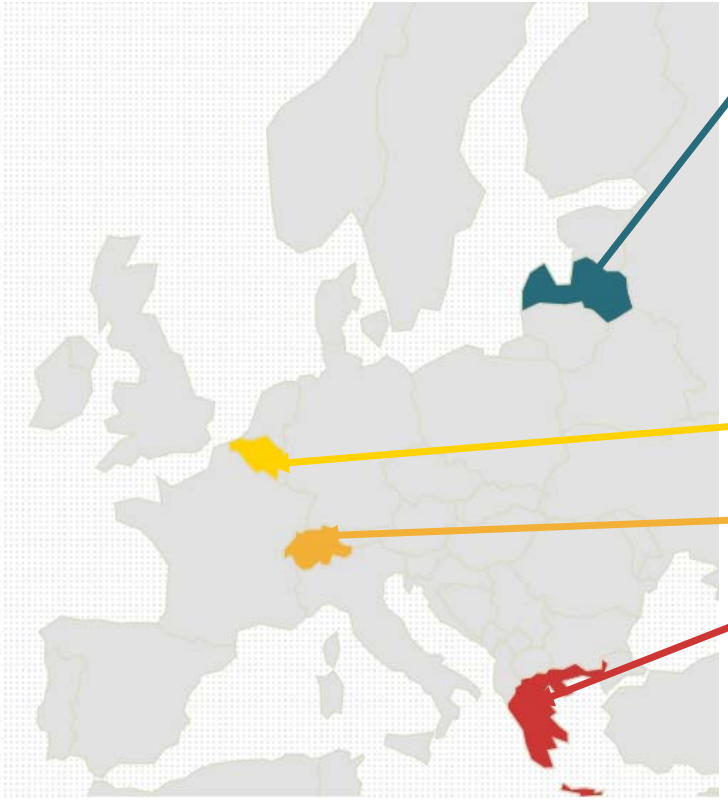
- **+10%** (2015 VS 2014 9 months)

Can't afford the treatment



- **+30% people stop treatment claiming insufficient funds as a reason**
- (2012 VS 2011 9 months)

THE LAST COUNTRY IN EU WITH A CO-PAYMENT FOR PEG. INTERFERON THERAPY



- **Latvia 75%**
- Lithuania 100%
- Estonia 100%

Belgium 75%+25%*

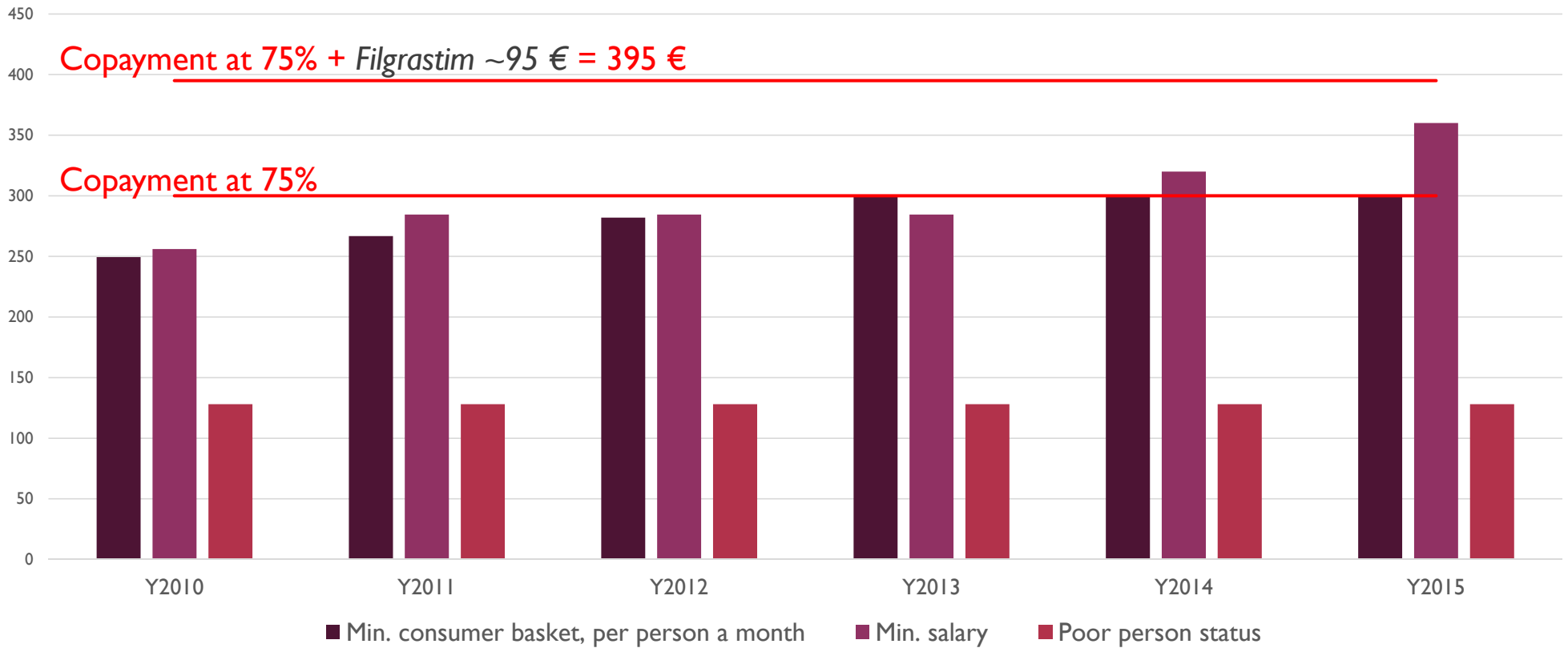
Swiss 90%+10%*

Greece 98%+2%*

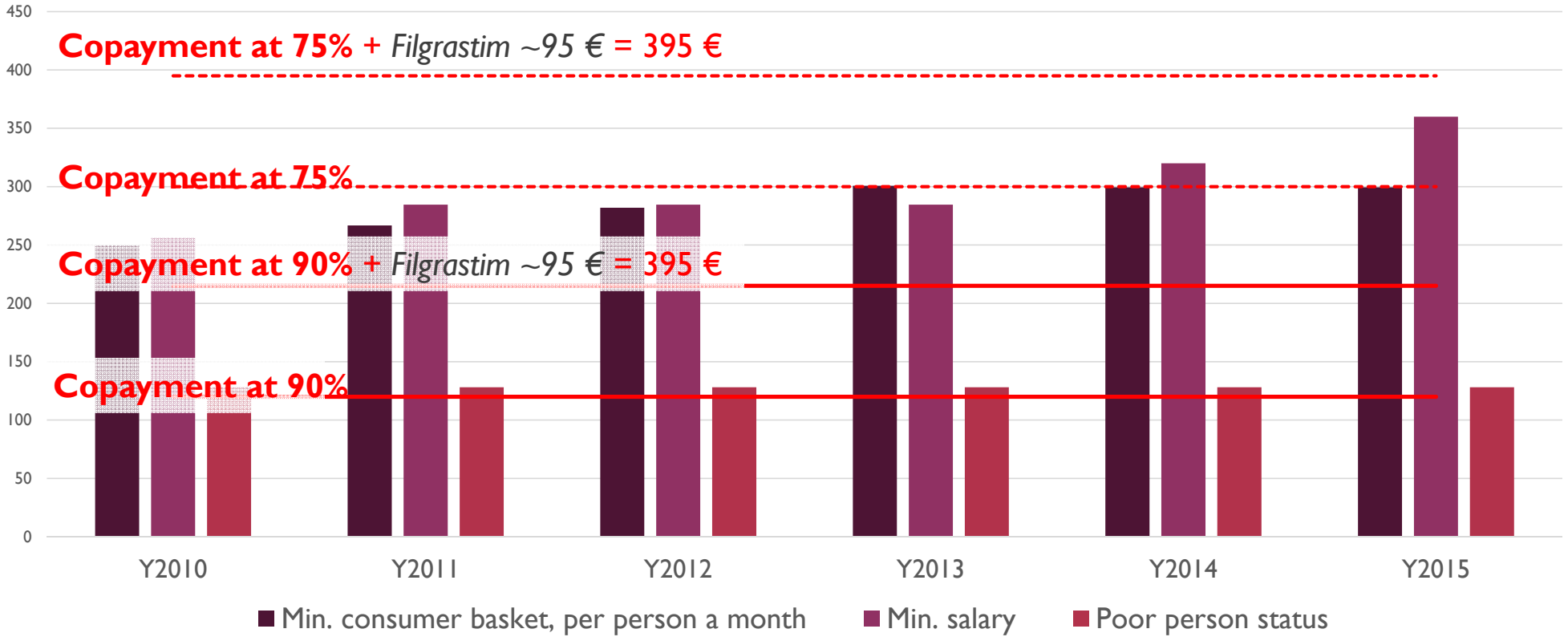
* State compensation + insurance

- Čehija 100%
- Horvātija 100%
- Lielbritānija 100%
- Nīderlande 100%
- Norvēģija 100%
- Serbija 100%
- Slovākija 100%
- Somija 100%
- Spānija 100%
- Turcija 100%
- Zviedrija 100%

STRAIN ON THE WELFARE & CO-PAYMENT 75%



STRAIN ON THE WELFARE & CO-PAYMENT 90%



LIFE WITHOUT HEPATITIS C

IT IS NOT ABOUT POLITICS, IT'S ABOUT LIFE

THE PLAN

IDEA

RESULT

THE PLAN

IDEA → RESULT

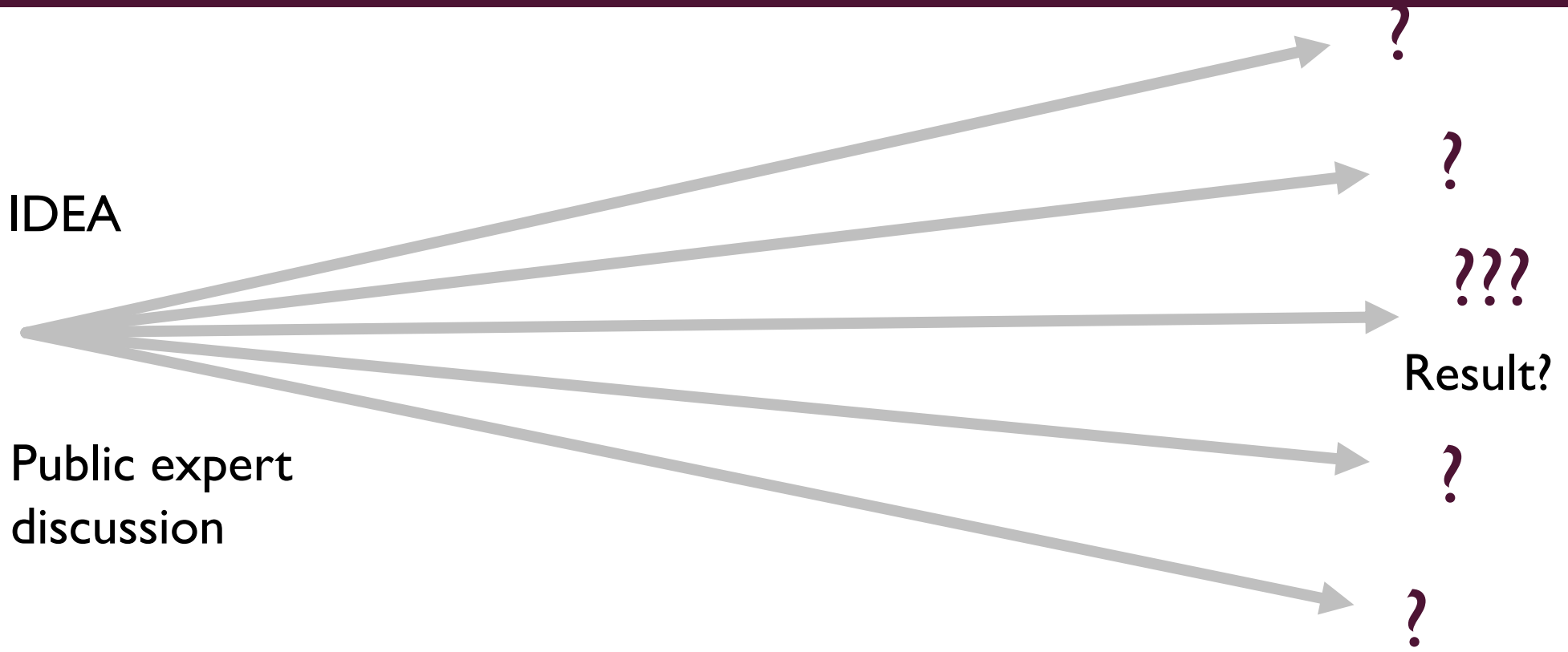
Public discussion

ManaBalss.lv

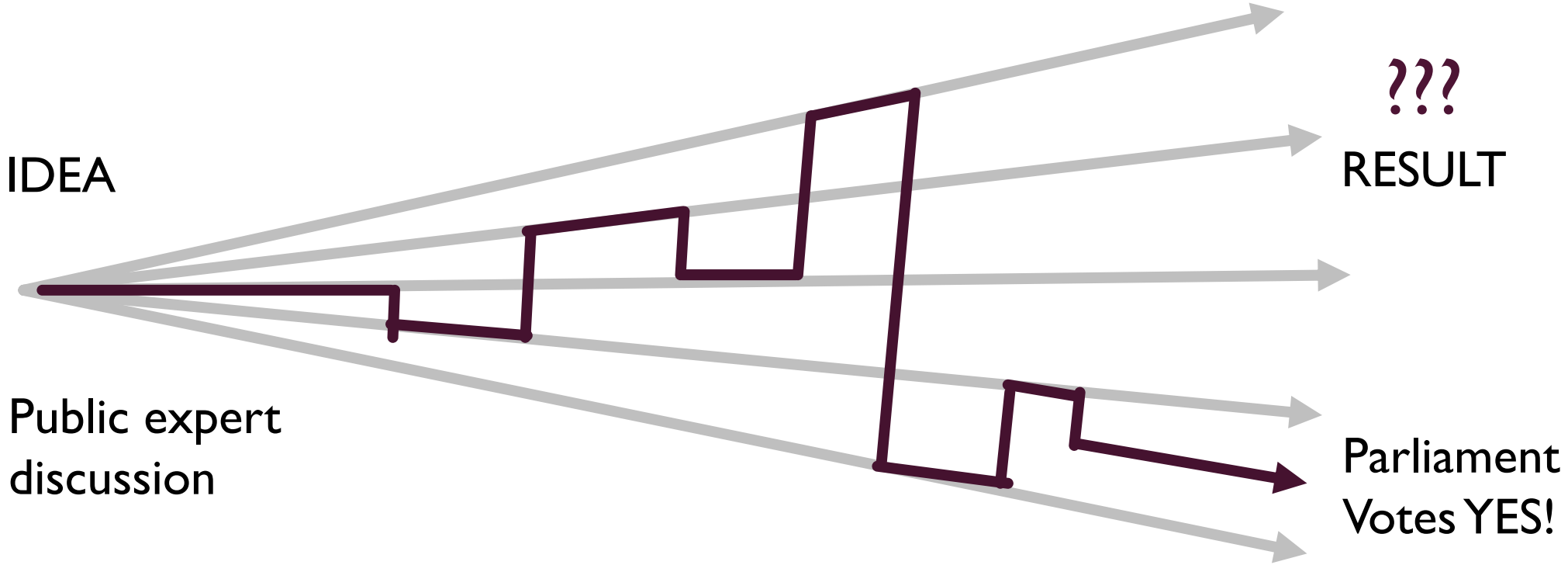
Outdoor campaign

Victory!

REAL LIFE (AFTER 6 MONTHS)



REAL LIFE (AFTER 18 MONTHS)



EXPERTS DISCUSSION (MAY 2012)

EXPERTS DISCUSSION (MAY 2012)

BALSO
PAR DZĪVI BEZ C HEPA

Nekad nav par vēlu...

PATIENTS STORIES

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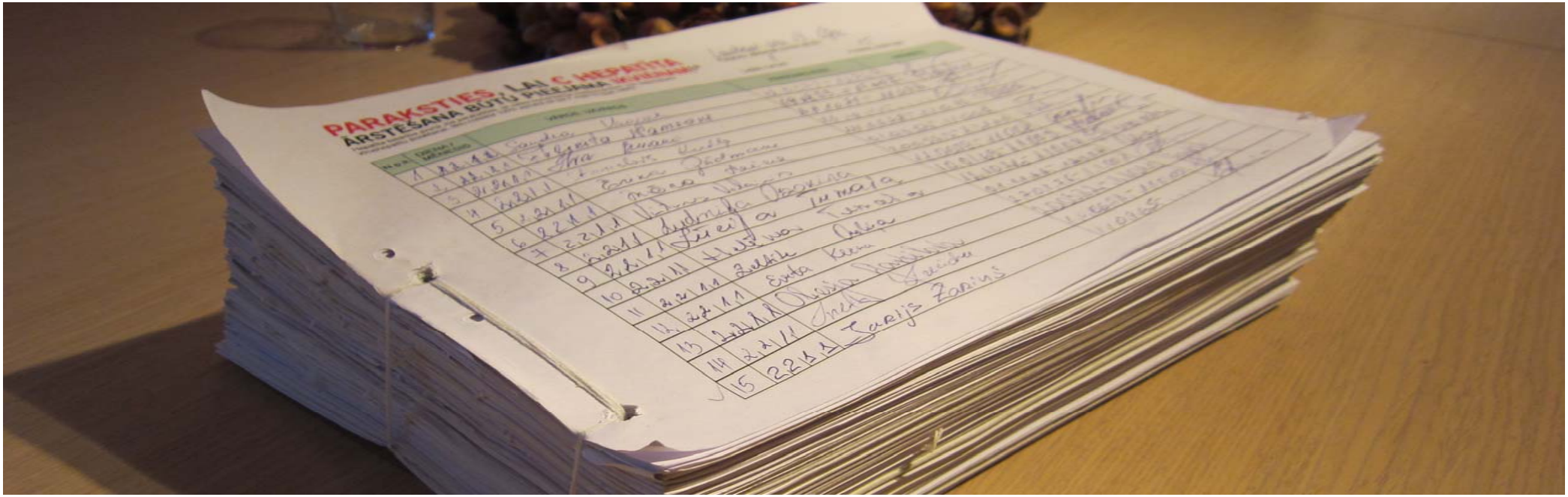
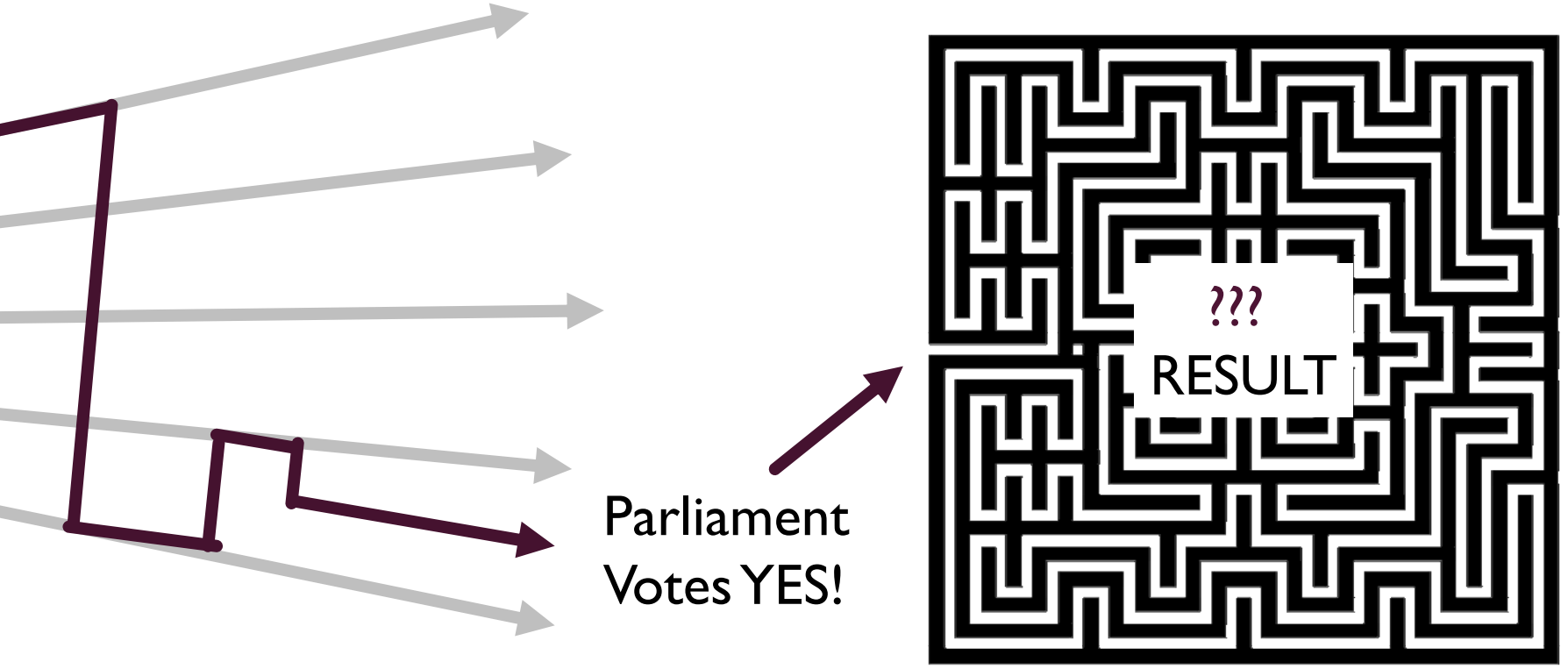
VAI ES ESMU VIENS NO 532
PAR DZĪVI BEZ C HEPATĪTA
BALSO
HEPATITS.LV

TALK NO EVIL!...



MORE THAN 13 600 SIGNATURES

REAL LIFE (AFTER 24 MONTHS)



HOW MUCH DOES IT COST?

HUGE, AMOUNT OF MONEY

- To raise state compensation to 90% we need… a lot??

~4,27mil € *

or 1,34 mil. €

* - National Health Service and Health ministry calculations

CAMPAIGN TIMELINE

13600+ sign.

13600+

Parliament

YES

75% → 90%

children 100%

2014. budget

Dec. 2012

May

2013

2014

STATE BUDGET 2014 … AND … ;-(

100% COMPENSATION FOR CHILDREN

CAMPAIGN TIMELINE

13600+ sign.

13600+

Parliament YES

75% → 90%

children 100%

2014. budget

Dec. 2012

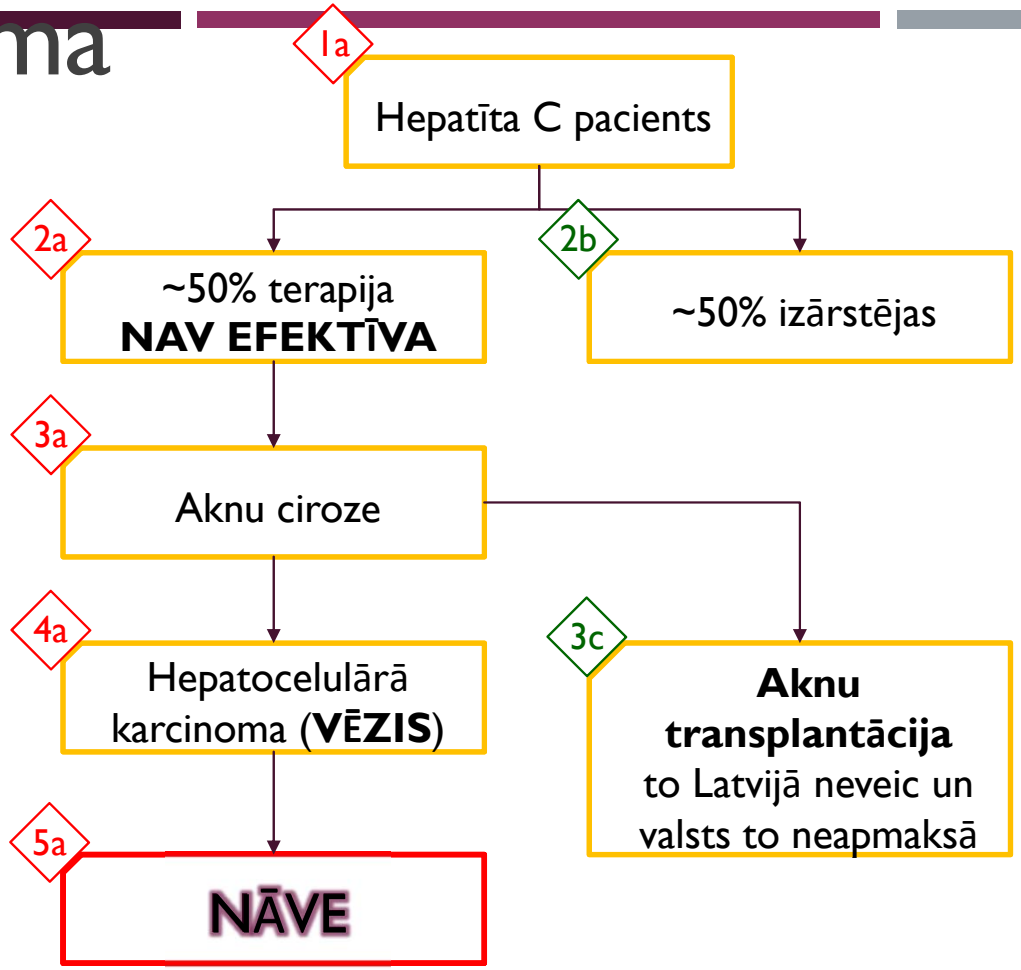
May

2013

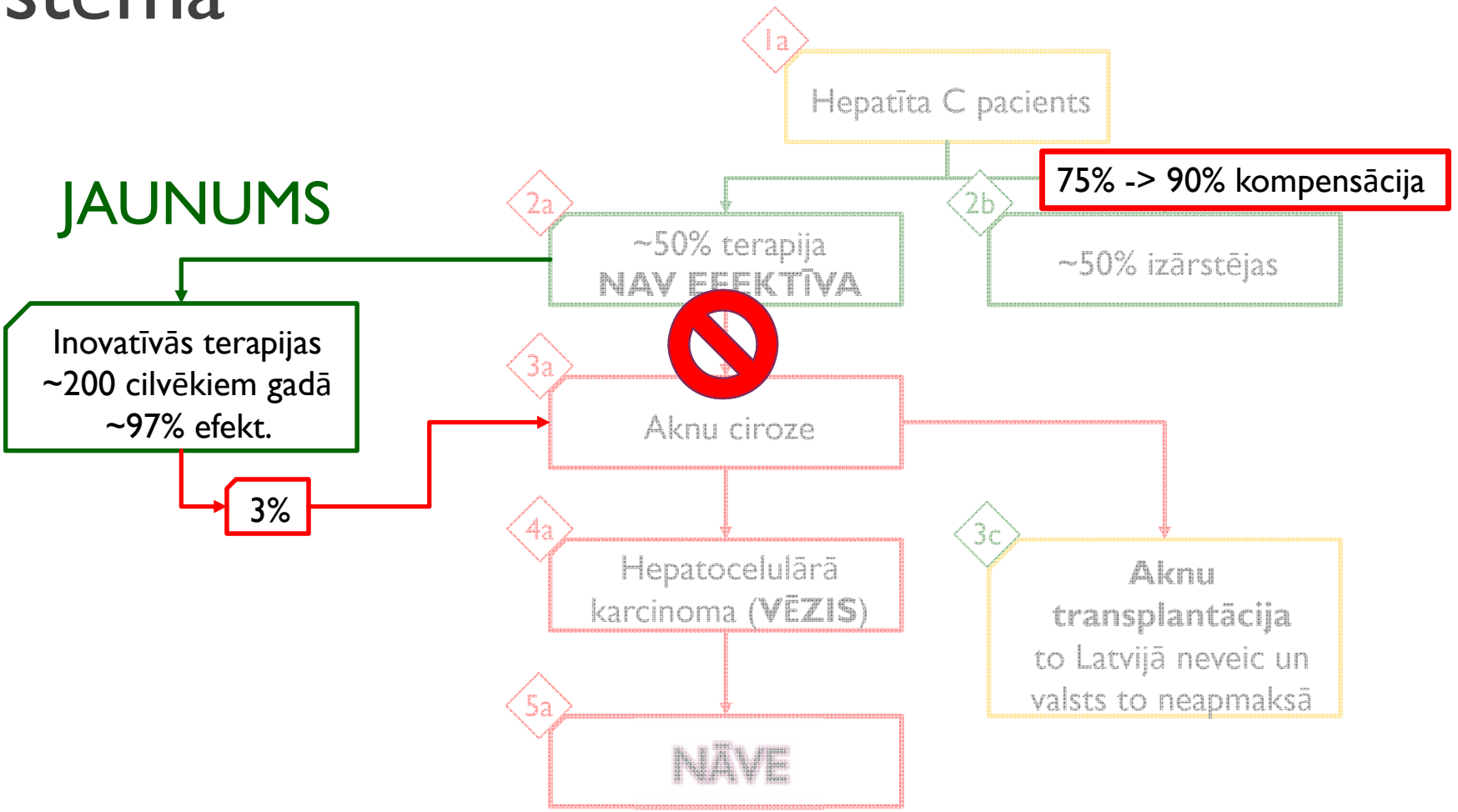
2014

Esošā sistēma

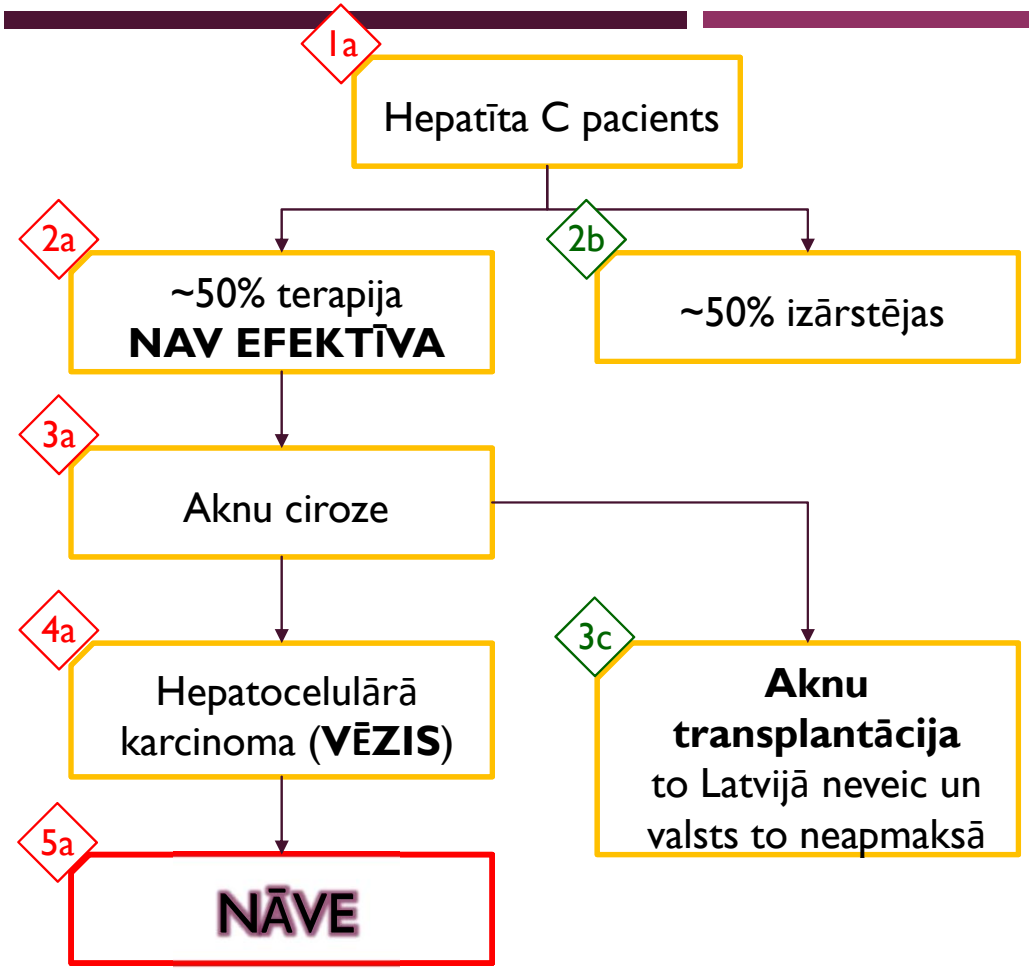
(3,2m€ / gadā)



Jaunā sistēma



ZUDUMI SISTĒMĀ



2A	2014. gadā valsts tērējusi 3,18 milij. € esošajai (vecajai) terapijai, ~50% pacientu šī terapija ir neefektīva. Laikus terapiju pārtraukt nav neviena interesēs, jo nav citu alternatīvu	1,59m€
2A	2015. gadā ražotāji par 20% samazinājuši cenu esošajai terapijai	0,63m€
2B	Ārstējoties pacientam ir augsts līdzmaksājums (200-300€) un virkne papildus izdevumu. Atbalstam tiek ņemtas slimības lapas, 1. un 2. grupas invaliditāte, kas tērē valsts līdzekļus	3,45m€ 0,38m€
3A	Ik gadus ārstē ap 967 pacientiem (2013)	0,28m€
4A	Ik gadus ārstē ap 145 pacientiem (2013)	0,16m€
Abām grupām piešķir 1. grupas invaliditāti		0,11m€

IEGUVUMI SISTĒMĀ

Ja ievieš jauno sistēmu
vairs nelietderīgi netērēs

2,22 m €/gadā

no esošā veselības budžeta

un izdevumi
4,38m€ apmērā
pakāpeniski mazināsies ar katru gadu

ZUDUMI SISTĒMĀ

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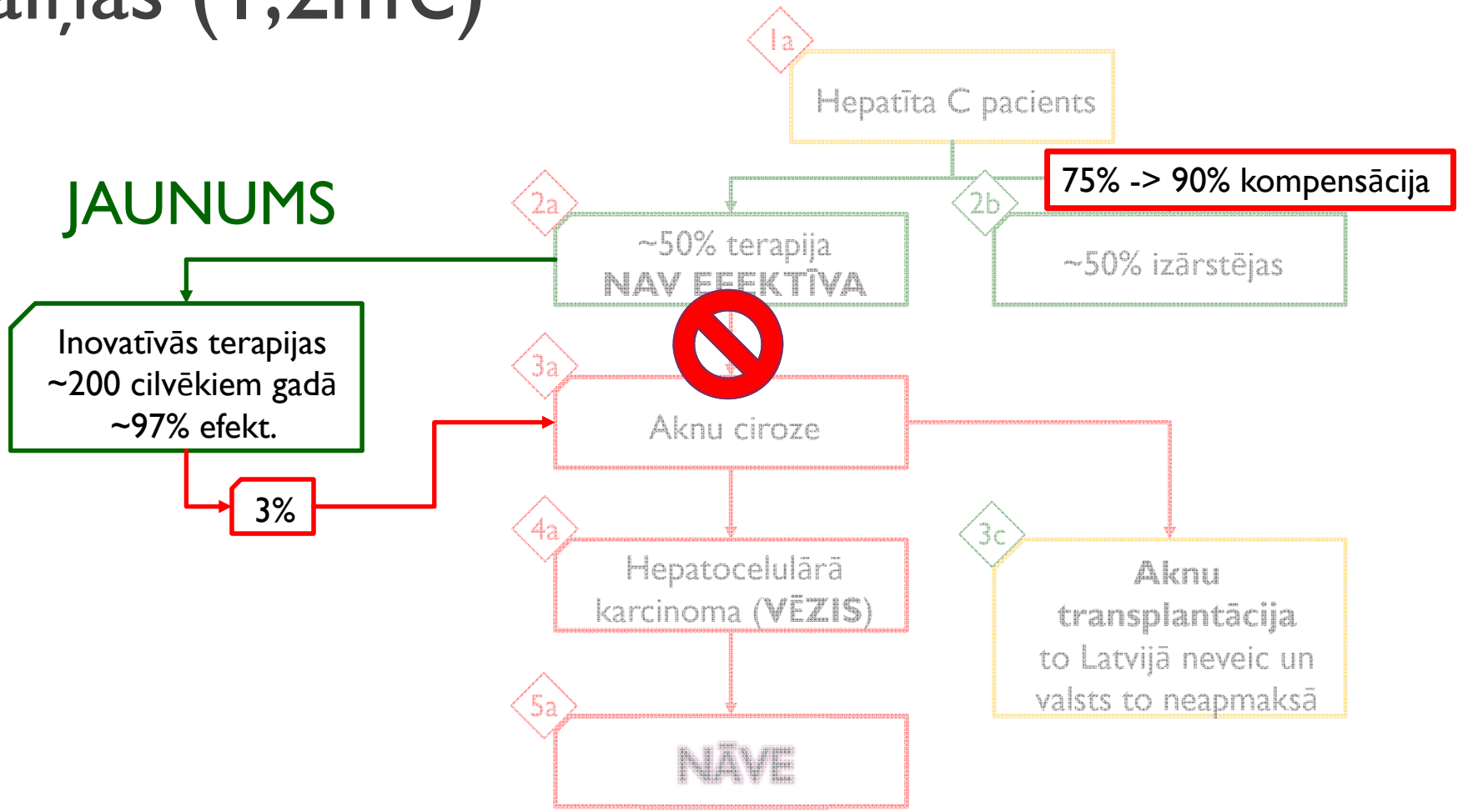
2,22 m €/gadā

no esošā veselības budžeta

un izdevumi 4,38m€ apmērā pakāpeniski mazināsies

Izmaiņas (1,2m€)



ŠIS VĒL TIEK PAPILDINĀTS

Vecā sistĒMA

- Situācija ik gadu pasliktinās
  - Inficēšanās risks palielinās
  - Tēriņi turpinās pieaugt
  - NELIETDERĪGI IZMANTOTI VALSTS LĪDZEKĻI
- 2013.g. inficēto skaits var sasniegt jau 50k
- Ap 20'000 cilvēku mēs pat nevaram ārstēt

Jaunā sistĒMA

- Situācija uzlabojas ik gadu
  - Ir iespēja izārstēt gandrīz visus pacientus (97%)
  - Inficēšanās risks pakāpeniski samazinās
  - Tēriņi ar laiku mazināsies
  - ESOŠOS LĪDZEKĻUS NEIZLIETOS VELTI
- Neārstējamo skaits ir tikai 1200

CAMPAIGN TIMELINE

New minister

Dec 2015

Constructive discussion + media pressure

FINALY!

Public discussion

Nov 27

The BUDGET 2016

Nov 30

?

Oct 2015

Nov 3

Nov 30

2016

IN CONCLUSION

EVERYONE AGREES – IT'S A PROBLEM

HEALTH IS STATE PRIORITY 2015, 16.. 17

HEPATITIS C IS HEALTH MINISTRY'S PRIORITY IN 2016

MOST LIKELY WELL GET 6,5 MIL.€ IN 2016

FOLLOW UP ON DISTRIBUTION OF FUNDS

WHO ARE WE

WERE

- HEPATITIS NGO LATVIA
- 11. years of patients right advocacy
- ¬ 250-300 registered members, 5-40 active members
- 15… 3…1 activist(s)
- Single person orchestra for many years
- Fighting for higher state compensation level (mostly)
- Manning the HELP-LINE for ¬10 years

Life is paradoxically coincidental to the ironical tyranny applicable to the unparalleled definition of reverse entropy.

THE REAL CHALLENGE

- Who is continuing the HELP-LINE
- Who is aiding the prevention and awareness campaigns?
- Is the threat really gone?

So long, and thanks
FOR ALL THE FISH!

THE REAL CHALLENGE

- Who is continuing the HELP-LINE
- Who is aiding the prevention and awareness campaigns?
- Is the threat really gone?
- Is it us or the society?
- Who will take over and with what agenda?

THANK YOU, FOR YOUR TIME AND SUPPORT!

PALDIES!

HEPATĪTA BIEDRĪBA:

Kristaps Kaugurs +371 28321777