

Prevention and control of viral hepatitis: Role and impact of liver patient groups in Europe.

Belgium:
CHAC & VHC



1) History of the organisations

- Belgium has two associations operating in their own language.
 - **CHAC: Carrefour Hépatites – Aide et Contact asbl**
French-speaking – Founded in 2001
 - **VHC: Vereniging voor Hepatitis C Patiënten**
Dutch-speaking – Founded in 1999

Why?

- To help patients
- To lobby for a national prevention and patients care plan

2) Objectives and role of the organisation

- Unite fellow-sufferers
- Gather and distribute information
- Claim prevention and battle against Hepatitis
- Draw authorities' & medical professions' attention to Hepatitis
- Look after our members' interests
- Give information to the media
-

3) How is it organised?

- VHC and CHAC are organisations with only volunteers: president, secretary, treasurer, and a few helping hands.
- All decisions are made in common agreement during our meetings.
- We work together with an advisory board from eminent doctors.

4) Target audience

- Target audience:
Patients and their family, risk groups, government, media and medical world.
- How is your organisation reached by its target audience?
Information phone line, e-mail, a newsletter (paper and digital version) about viral hepatitis, forums in different cities, a website and a on-line forum.
- VHC has 700 members and CHAC ~ 1000
- Conferences in schools and nursing schools + parliament commissions (to prepare projects of laws)

5) Services and Activities: General

- Dissemination: all information is checked and approved by doctors
- Services to patients: information phone line, magazine, information brochures, website and an on-line forum.
- Lobbying with the several governmental levels in Belgium
- Research: follow-up of the latest national and international research
- Survey organised among 800 patients on the perception of their illness
- Publication of a book with testimonials and medical information from specialists
- Organising conferences and question evenings in several hospitals
- Public and media events (e.g. march in Brussels)

6) Services and Activities: Prevention

- Own information folder
 - Mailing to all the generalists
 - Distribution in schools, drug prevention centers, ...
 - ...
- Symposia to inform the population
- Prevention brochure for footcare
- Guidelines for tattooing
- National campaign VHA-VHB vaccination (with partners)
- Trying to obtain reimbursement of hep A and B vaccination for chronic hep C patients
- Project of law regarding prevention

7) Support and Financing

- Membership fee
- Donations. Every gift above 30 euro is tax deductible.
- Fundraising events: selling cookies, CD-Rom, books, ..
- No structural governmental support (occasionally, for particular actions some support is given)
- Pharmaceutical industry: support from local branches
- Foundations: no

8) Other related groups active in your country

- Belgian, Flemish and Walloon patients' platform
- Physicians from Flemish and Walloon hospitals
- Association of liver transplants
- Belgian Association for the Study of the Liver
- Association Flemish and Walloon gastro-enterologists
- Different drug prevention and HIV associations
- Prisons

9A) Strengths

- Only 2 Hepatitis patients' associations in Belgium
- Main organisations providing information to media and patients
- Organising a national campaign for the international Hepatitis Day
- Support from all hepatologists and the BASL
- Despite intensive lobbying,
there still is no national information and prevention plan !

9B) Strengths toward improved prevention

- Reimbursement of medication for most patients
(unfortunately not for children, patients with normal ALT, relapsers, acute chronic hepatitis C)
- Trying to set up a national prevention campaign
- Created more awareness among medical professions and governments

10A) Challenges

- No government support
- Collaborators – not enough people who can help with the daily efforts of our organisations

10B) Challenges and thresholds toward support of improved prevention

- Obtaining government support and funding
- Interim government – all health issues are on hold till March 2008



Some VHC Patients Activities

More than 100 people at the information conference
with different renowned specialists
during the **National Hepatitis Day** !



*Media coverage
in several
newspapers and
on national
television*

Legendary **70's rockband MC5**
testifying about the hep C contamination
of one of its members



Publications

- Publication of a book with the latest information on and testimonials about hepatitis C
- Dissimination of our magazine (4 times / year)





Some CHAC Activities

Creation on 7 May, 2001



Participation in Working groups (Senate, Chamber, others...)

Information forums

School Lessons

Shock Actions
(marches, petitions
TV and radio
Broadcasts...)

Help line

JUNE 2004 Creation of ELPA

→European dimension

Publication of a quarterly newsletter

Activity 7 days a week

MAY 2004 : First National Day



**March in Brussels
2002**

**March in Brussels
2005 with VHC Patienten**



**TOUS
ENSEMBLE
CONTRE LE VIRUS
DE L'HÉPATITE C**

- Film informatif
- Artistes de rue
- Artisans, brocanteurs
- Restauration
- Baptêmes de l'air en mongolfière
- Parcours santé...
- Activités ludiques pour les enfants
 - Orchestre "Les Fous du Roi"
 - Karaoke...
- Match de foot
coup d'envoi donné par
Marc Wilmots

Présence de nombreuses personnalités
du monde associatif, culturel et politique.
Présence sur place de Jacques Sondron
qui caricaturera à grandes dents qui le veut.

en soirée,
Souper - spectacle
animé par
Georges Pradez
avec
Marc Herman



Journée Nationale de lutte contre l'hépatite C.

Au Hall des Sports Roi Baudouin à Jodoigne
Le dimanche 23 mai 2004 de 10 heures à l'aube

PAF : 2 € à l'entrée du site. PAF pour le souper spectacle : 60 € (40 € pour les membres du CHAC)

Renseignements
& Réservations :

061/26.68.90
0405/38.46.61
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May, 2004

National Journey

Creation of a film about viral hepatitis



May, 2005

National Campaign

(with partners)

VHA-VHB Vaccination

Vaccination contre les hépatites A et B

Je signe maintenant
un contrat pour la vie!



UNE SIMPLE VACCINATION POUR UNE PROTECTION À LONG TERME

1. New England Journal of Medicine 2004; 351:2052-6. <http://www.nejm.org/lookup/04052004/00> - 2. Clinical Infectious Diseases 2004; 38:708-15



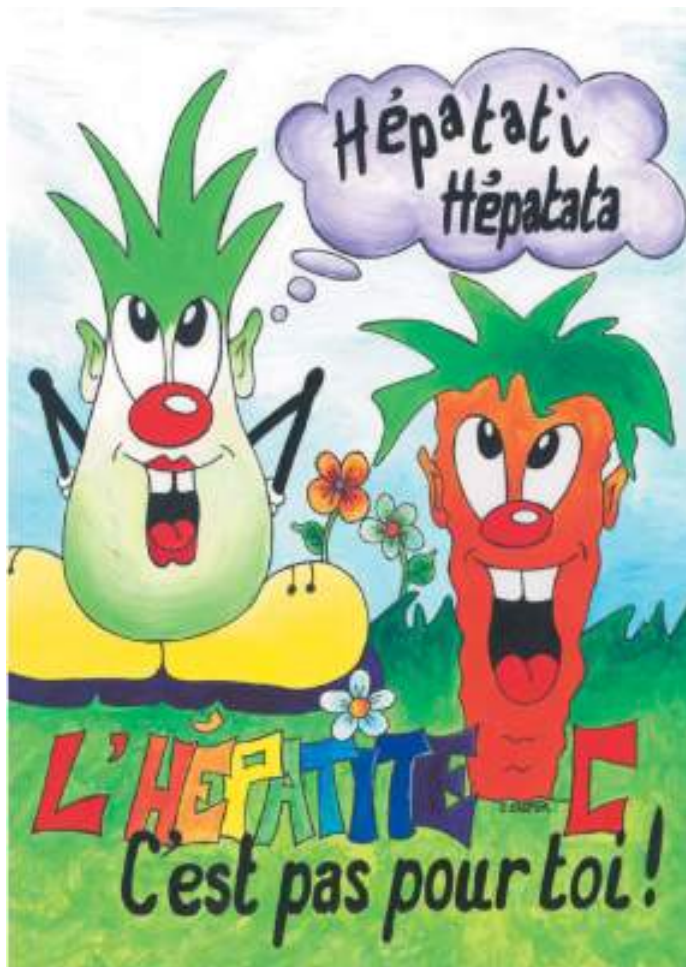
OPHACO



Le Journal
de médecine



A book for children



A poster, a flyer



Many forums, meetings ...



Tournai



Namur



Belgian Week
Of
Gastroenterology

▶ The Minister

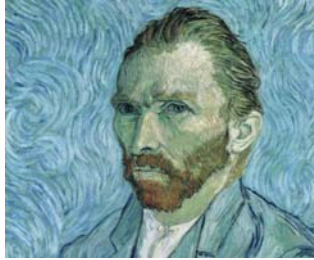
Our stand



2006 - National Survey



What is she going to say?



What is he going to hear?



What does she have in mind?

"Vivre ou avoir vécu avec une hépatite virale"



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Nobody's Unpredictable  Ipsos

Août 2006

Réf. 714BZ01

Awareness amongst medias

Hépatites : dépistage essentiel

Des délais particulièrement longs avant le diagnostic

estime que quelque 100.000 personnes, en Belgique, sont porteuses du virus de l'hépatite C, et que la moitié l'ignorent.

Hormis le fait – mais ce n'est pas rien – qu'ils soient difficiles à supporter sur le moment (en raison de leurs effets secondaires), les traitements

La Dernière Heure

ACTUALITÉ

1^{er} octobre: Journée mondiale de l'hépatite C

Le CHAC repart à l'attaque

La troisième journée mondiale de l'hépatite C est l'occasion pour le CHAC de présenter les résultats d'une enquête menée auprès des patients atteints d'hépatite B et C. En filigrane, on retrouve les mêmes revendications qui reviennent chaque année, faute d'avancées significatives dans la problématique des remboursements.

Hépatite / Enquête nationale

Le virus fait encore des ravages

Le Soir

Actualité Belgique

SAMEDI 30 SEPTEMBRE 2006 21

SANTÉ JOURNÉE MONDIALE

20 ans de vie commune avec le virus de l'hépatite C

Daniel raconte l'enfer de cette maladie qui touche 100.000 Belges

Sud Presse



Le journal
du médecin

Une enquête révèle que seulement un tiers des personnes non traitées se seraient vu prescrire un traitement.

Sensibilisation

Il faut dépister l'hépatite au plus tôt

Le dépistage et diagnostic précoce constituent le thème de la journée mondiale.

Le thème de la Journée mondiale des hépatites qui se déroulera le 1^{er} octobre prochain.

A quelques jours de cette journée, l'association de patients

et le diagnostic d'une hépatite C est de 14 ans pour 60% des malades atteints par l'hépatite C.

La plupart sont victimes de l'épidémie des années 1940-1980,

La Libre Belgique



May, 2007- Senators awareness



Copyright <http://tatactic.be>

QUIZ

Individual test Fibroscan

Signature CHAC Charter





RTL coverage + Questions in live

You tube

-http://fr.youtube.com/watch?v=_NosAICXDgQ





WHAD 2007

1 October 2007

A law-project co-signed by representatives of all the French-speaking democratic political parties of the country.

The Senate,

- 1. Considering the growing number of people contaminated by hepatitis B and C in Belgium and on international level**
- 2. Considering that 50% of the Belgian population ignores this disease, its symptoms and its consequences**
- 3. Considering the crucial impact in terms of cure and non-contamination of an early diagnosis of hepatitis**
- 4. Considering the urgency to establish a list of measures to be taken to fight against hepatitis**
- 5. Considering the insufficiencies on the level of refunds of the various treatments**

Requests to the government:

- to organize a large national campaign of sensitization to hepatitis B and C mainly centred on the risk factors, the symptoms and the importance of an early tracking as well as simple measures of prevention for the general public, the nursing staff and general practitioners.
- to adopt a global multi-annual plan, in co-operation with the Regions, against hepatitis, describing all the measures and initiatives to be put in place within this framework
- to think of a broader and more optimal refunding of the treatment of hepatitis which would cover the expenses of all persons suffering from hepatitis B and C, as well as their vaccination against the virus of hepatitis A and B because the super-infections strongly increase the death rate for these people.
- to put in place tax incentives for the research and development of new treatments and of a vaccine against hepatitis C
- to improve the access to the insurance and the loans to people contaminated by hepatitis, while founding a committee of medical experts, independent of the insurance companies and mutual insurance companies, charged to carry out the evaluation of the risk of these candidates with the insurance and the loans.

CHAC Objectives in 2008

- ✓ **Mobile Panel for hepatitis B only**
- ✓ **Booklet entitled « The ABC of viral hepatitis » (250,000)**
- ✓ **Survey on hepatitis B (Distributed by specialists and on the website)**
- ✓ **Survey on viral hepatitis for general public (QUIZ)**
- ✓ **A new flyer (250.000)**

At the political level

- ✓ **Bill signed by many senators (various parties) - National plan to fight viral hepatitis**
- ✓ **Press conference at the Senate + patients' testimonies**
- ✓ **Survey announcement**

The new flyer.

On the trail of Viral hepatitis

Using this viral hepatitis flowchart, move from box to box to help you find out more, understand the disease better or give advice to those around you...
Getting tested is easy! A simple blood test is all it takes!

- ♥ Risk factors
- ♥ Screening
- ♥ Treatment
- ♥ My liver



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Continued
on reverse



11) Conclusions

Patients groups in Belgium are vital:

- For the patients
- For prevention within risk groups
- For disseminating information
- To keep the government alert for the lack of a prevention campaign