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…)

JUNE 2004 Creation of ELPA →European dimension

Publication of a quarterly newsletter

Activity 7 days a week

MAY 2004 : First National Day

Information forums

School Lessons

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

Help line
Creation of a film about viral hepatitis

May, 2004

National Journey
May, 2005
National Campaign
(with partners)
VHA-VHB Vaccination
A book for children

A poster, a flyer
Many forums, meetings ...

Belgian Week Of Gastroenterology

The Minister Our stand
"Vivre ou avoir vécu avec une hépatite virale"
Awareness amongst medias

La Dernière Heure

Sud Presse

Le journal du médecin

Le Soir

La Libre Belgique
May, 2007- Senators awareness

QUIZ
Individual test Fibroscan
Signature CHAC Charter
RTL coverage
+
Questions in live

You tube
- http://fr.youtube.com/watch?v=_NosAlCXDgQ
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.
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