Prevention and control of viral hepatitis:

Role and impact of liver patient groups in Europe.

Bulgarian National Association for Fighting Hepatitis “HEPASIST”
History of HEPASIST

- Before 2005:
  - “Hepatitis = the disease of the dirty hands”
  - There were no organized patient groups for support and to stand for patients’ rights
  - The civil society was in its initial stage
  - The only prevention measures were taken by health authorities – vaccination program for newborn since 1992
  - It was difficult to find information in Bulgarian for most hepatitis issues
  - Few medical specialists (mostly in big cities)

- HEPASIST was founded in the beginning of 2005 by seven people - patients, relatives, doctors and media specialists.
Objectives and role of HEPASIST

- **Informing the society**
  - Awareness raising - public media events, information campaigns, books, leaflets, etc.

- **Prevention**
  - Vaccination awareness and fighting with prejudices against vaccines
  - Providing vaccines for marginal and risk groups
  - Access to screening and early diagnostic of viral hepatitis

- **Standing for patients rights**
  - Establishing contacts with health institutions - Ministry of Health, National Health Insurance Fund, National Center for Infection Diseases etc.
  - Legal support for patients
  - Civil society actions for access to treatment
Structure of HEPASIST

- Honourable chairman (1 voluntary) – a patient with mostly representative role
- General secretary (1 voluntary) – managing and representative functions
- Coordinators (2 paid) – executive stuff
- Medical consultants (3 paid) – medical students who give on-line consultations, work with patients and answer the Toll free line
- Lawyer (1 paid)
- Medical advisors (5 voluntary) – medical specialists
- Members of the organization
- Volunteers
Target audience

- **Patients** with viral hepatitis
- **Relatives** of patients with viral hepatitis
- **Members** – over 600 legal members from all over Bulgaria – mostly patients and relatives
- **Health Authorities** – Ministry of Health, National Health Insurance Fund, etc.
- **Media** – print, television, radio, internet and interactive communication channels
- **Healthcare specialists**
Services and Activities: General

- Dissemination of information
  - [www.hepasist.org](http://www.hepasist.org) – the most informative site in Bulgarian, interactive options, on-line consultations, patients` forum, news, etc.
  - Toll free line – 0700 10 515 – patient support by medical consultants
  - Information books and leaflets for prevention, treatment etc.
  - Awareness information and advertising campaigns - media partnerships for several campaigns – “Give blood! Get free testing”, “It is easy to get infected. It is also easy to be protected.”, “VOTE for the patient rights”, “Get tested!”; press-conferences and media events - hundreds interviews, TV and radio shows, on-line and print publications.
За финансирането на програмите са необходими 8 млн. лева.

Независимо от забележките в някои от страниите, включително и България, в последните две години са сделани напредъци. От съответния документ, трябва да бъде поставено внимание на необходимостта от дори по-големи ресурси.
Services and Activities: General

- **Activities for access to treatment**

  - In March 2006 the treatment program for chronic viral hepatitis was stopped due to lack of financing.

  - HEPASIST was the main initiator of all activities for standing the patients' rights – Patients’ protests, civil and public claims against institutions, round tables, wide media campaign for patients' rights, international support (ELPA and members).

  - **RESULT:** In February 2007 the treatment program was re-opened, the health authorities promised to partner with HEPASIST as representative of viral hepatitis patients in all future activities.
Общо касание

Бюджет по програми за 2007 г.

Общо 36 млн. лв. от бюджета на Националната здравноотчисления каса ще отидат за съкъсствувашщо лечение. Тоа обяви директорът на НЗОК д-р Румяна Петрова. Бюджетът на касата за 2007 г. е 270 млн. лв. Десетте програми за лечение са: хроничен вирусен хепатит, хепатит B и C, безплодие при жените, остеопороза, множествена склероза, хронична бъбречна недостатъчност, эндометриоза, ранен централен пуберет, хипоардиоцитози.

Пламена Димова

Финансовата рамка от 36 млн. лв. за пръв път ще гарантира равнопоставеност на пациентите в разпределението на лекарствените продукти. Приемът на документи за включване във десетте програми започва на 12 февруари. Лимит в броя на пациентите няма - разпределението на средствата се определя от лекарите. Критерите и условията за включване остават без промяна от 2006 г. Ще се следи строго за потреблението на лекарствата. Проблемът с, че Румяна Петрова обяви, че са измислиха да имат неотдавна здравствения министър Евцунов да покаже мерки за възстановяване на баланса между здравеопазването и социалните разходи.
Services and Activities: Prevention

Fund raising campaign for providing vaccines

- The spring of 2006 was full of rain floods in many Bulgarian regions with heavy material damages
- HEPASIST initiated a fund raising campaign for providing vaccines for the affected poor regions
  - Partnership with the national television Nova TV - TV show “Who wants to be a millionaire?” – Ministers, Mayors and children from the affected regions played and donated the money for the prevention campaign
  - Partnership with the Bulgarian “Big brother” – VIP Brother edition
  - Two mobile operators opened lines for SMS fund raising
  - GlaxoSmithKline (GSK) donated vaccines
Services and Activities: Prevention

- HEPASIST used all money to provide vaccines (Havrix and Twinrix) for the marginal and risk groups in the flood regions.

- Shortly after the campaign a Hepatitis A epidemic started in a gypsy area and spread in many other regions of the country. Due to bureaucracy the Health Ministry delayed with the vaccination of those regions. HEPASIST in collaboration with UNDP and GSK provided vaccination for children in mixed schools – Bulgarians and Gypsies.
Ваксинират за хепатит пострадали от наводнения

Националното служение за борба с хепатит „Хепасист” събра дарения от ваксини срещу хепатит за райони, пострадали от тазгодишните наводнения. Средствата са спечелени от участниците в предаването „Станни Богат” през май. Тогава на стола срещу т.е. в продажба Ники Кънчев съдейства министърът Емил Ерем и Асен Гагаузов, кметовете на Видин и Никопол, както и деда на споделените и споделени вътрешните качества. Специално за инициативата М-Тел и Глобул отвориха телефонни линии за набиране на средства. Целта сума 74 258 лв. беше предоставена на „Хепасист” и с нея бяха закупени 1000 дози комбинирана ваксина за хепатит A и хепатит B и 500 дози от детската форма на ваксината за хепатит A. В инициативата се включиха и фармацевтични компании „Гласко Смит Клин” и „Санеко Клин”, която дари 180 дози от комбинирания ваксина за хепатит A и хепатит B и 400 дози от детската ваксина за хепатит A. Ако събращата сума не бъде усвояна на общницата Видин и Никопол, тя ще бъде разпределена между всички съседни градове на банята. За щастие хепатит A не се превръща в хроничен, но половин випуск след преболедуването му трябва да се следва строга диета. Ваксината е най-сигурната защита.

найт, че са т хепатит

Блажинска вирулентите на хепатит B и С, знаят, че са болни, обяви вчера в – секретар на Националното агентство „Хепасист”. Данините на иматология и трансфузиология продадени в Стара Загора за 2005 г. обаче 28 751 души, носители на маркери за хепатит B/С на хепатит C, обяви министърът на здравеопазването Асен Гагаузов.

Слава РАДОСЛАВОВ
Проблемите с хепатита - със съдействието на държавата
Services and Activities: Prevention

- Awareness campaign “It is easy to get infected. It is also easy to be protected.” – in collaboration with GSK
  - Media partnership – the advertising image was published in main print media
  - Toll free vaccination line was launched
  - The vaccination centers and specialized cabinets across the country were popularized and extended their working hours during the campaign

- Screening campaigns (in collaboration with ROCHE) – During 2007 more than 3000 people (public and medical stuff) were screened for Hepatitis B and C in 5 major cities. Information about prevention was given to all tested people and to the media. The infected were redirected to local specialists for further diagnostic.
Рискуваш всеки ден?

Анонимно и безплатно изследване^ *

Хепатит В и Хепатит С

Място:.................................................................
Дата:.................................................................
Час:.................................................................

*Изследването е със скринингови цели. Извършва се с капка периферна кръв и резултатът е готов след няколко минути.

Хепатит? Тествайте се get Hepatitis Tested!

Hepatitis? Kendim test et!

Изследвай се безплатно!
Дари кръв!

Изследвай за:
• Хепатит В
• Хепатит С
• HIV (СПИН)
• Сифилис
• Кръвна група

Начините на дарене: дарение в болница или център за кръв на 0700 10 515

www.hepasist.org

WORLD HEPATITIS DAY
1st October 2007
www.hepatitisday.info

Хепасист национално сдружение за борба с хепатита
## Support and Financing

<table>
<thead>
<tr>
<th>Group</th>
<th>Financing</th>
</tr>
</thead>
<tbody>
<tr>
<td>members</td>
<td>No membership tax. Members are participating voluntarily in some of the activities</td>
</tr>
<tr>
<td>private donors</td>
<td>Rarely – mainly mobile operators and media groups</td>
</tr>
<tr>
<td>fundraising events</td>
<td>“Who wants to be millionaire?” initiative</td>
</tr>
<tr>
<td>government</td>
<td>No financing</td>
</tr>
<tr>
<td>pharmaceutical</td>
<td>Mainly – Some companies support HEPASIST on monthly basis. We apply for financing for each different project.</td>
</tr>
<tr>
<td>foundations</td>
<td>none</td>
</tr>
</tbody>
</table>
National Association for Fighting Hepatitis HEPASIST is the only hepatitis patient organisation in Bulgaria. HEPASIST is in close collaboration with several patient groups that may have common interests:

- Kidney insufficiency and haemodialysis patient groups
- Drug users organizations
- HIV positive foundations – HEPASIST provided vaccination for HIV + and started a treatment program for few co-infected patients
- National Association of Patients with Transplantation
Strengths

- For almost three years since established HEPASIST has turned into a main source of information and support for hepatitis patients and their relatives in Bulgaria.

- The media trust the Association and participate in all its events. The activities of HEPASIST are usually widely covered by the main media.

- As a part of the civil society HEPASIST showed its strength to the Bulgarian health institutions. Nowadays, HEPASIST becomes more accepted as an important partner in the policy of the institutions related with viral hepatitis.

- The partnership with ELPA already showed positive results at national level.

- HEPASIST is sponsored by the main pharmaceutical companies for most of its activities.
Strengths toward improved prevention

- The professional team of HEPASIST has proved its ability in organizing awareness and information campaigns with large public and media impact.

- The efforts for collaboration with the related health authorities already started giving positive results in different preventive initiatives.

- The strong media relationships on national and regional level can be used in future activities.

- The organization has active members throughout the country that could be helpful in future prevention activities and events.

- Bulgaria has a vaccination program since 1992 that already showed effect and the number of infected between 0 and 16 years old drastically decreased
Challenges

- **National Hepatitis Strategy**
  - A multi-institutional working group is assembled to create a National Hepatitis Strategy till the end of April 2008
  - The Strategy should be adopted by the Minister of Health till June 2008
  - The Parliament should vote a budget for 2009 for starting the strategy

- Raising the number of treated patients each year, due to the high number of people, infected with the viral hepatitis

- Improving of the level of early diagnostics in Bulgaria

- Finding other sources of financing for the organization which will ensure its independent functioning

- Better collaboration with Institutions for improvement of treatment, diagnostic, awareness and prevention level
Challenges and thresholds toward support of improved prevention

- Improved prevention is the main part of the future National Hepatitis Strategy. Some of the measures in the strategy are:
  - Accessible information for the whole society and especially the marginal and risk groups
  - Access to free testing and diagnostics
  - Vaccination campaigns for risk groups
  - Educational programs for youths and medical stuff

- The Bulgarian Government has limited financial resources for prevention

- There are strong prejudices against vaccines in Bulgaria

- The collaboration with the health institutions is still difficult
Conclusions

- HEPASIST has become one of the strongest patient organizations in Bulgaria with growing impact on hepatitis policy.

- Even a lot have been done from the Government with the vaccination program since 1992 and the information campaigns provided by HEPASIST, there are still big thresholds in the Bulgarian society about hepatitis.

- The future National Hepatitis Strategy will be a big step towards the improved prevention in Bulgaria and will be a good basis for further activities for both – Government organizations and NGO’s.