Prevention and control of viral hepatitis: the role and impact of patient and advocacy groups in and outside Europe

Lucca, Italy
13-14 March 2008
Objectives

- Review activities, role, rationale and impact of patient and advocacy groups in Europe and the USA on prevention and control of viral hepatitis
- Share experience of international and national groups
- Identify limitations on the role and impact of such groups and define their strengths
- Examine role and impact of partners
- Identify lessons learnt and opportunities available
Background

- Hepatitis B poor cousin to hepatitis C and HIV/AIDS in Europe; poor (acute) or non-existent (chronic) data; hepatitis B only recently included in agenda of patient organizations (immigration, low socioeconomic status, inadequate provision of health care)
- Different diseases, different approaches to hepatitis B and hepatitis C; existence of hepatitis B vaccine (plus anti-vaccine lobby activities) complicates political case; no vaccine against hepatitis C
- Legislative moves and a "viral hepatitis" approach: EU, USA
- WHO Regional Strategic Plan 2008-2013
- Hot political themes: public-private partnerships and role of pharmaceutical industry; health of migrants; regional and global initiatives: immunization weeks, hepatitis days
- Many younger hepatitis B patients represent the failure of prevention
- Numerous patient organizations working in a competitive environment
- Broadening funding base - non-traditional donors
European policy recommendations

• Recommendations for better management of hepatitis B
• Partnership and consultative process
• Holistic strategy
• Social integration
• Clear and consistent message
• Reliable data through surveillance
• Screening, migrants, and human rights
• Cohesive vaccination policy
• European leadership, nations follow (and role of pharmaceutical industry)
European Immunization Week

• Remaining risk and need to counter influence of anti-vaccine groups
• Advocacy and communication (including now nongovernmental organizations)
• Sharing experiences
• Opportunity for synergies
• High-level involvement and engagement of main target groups
• Good media response
• Potential hook for hepatitis activities at national level (opportunity for amplification of message, e.g. Belgium)
Umbrella patient organizations in Europe

- **European Liver Patients Association**
  - 20 member patient groups in 17 countries
  - Achievements include: inclusion of hepatitis in the work programme of the European Centre for Disease Prevention and Control; written Declaration from European parliament
  - Focus on promotion of screening (EU council recommendation for screening)
  - Coordination of campaigns and message
  - Generate reliable and comparable surveillance data at EU level using ECDC criteria

- **European Patient Group for Rare Diseases**
  - Patient-driven, nongovernmental, non-profit organization including >310 member organizations in 34 countries
  - Pan-European voice, able to speak for millions of patients; multilingual
  - Activities include networking, advocacy, policy development, access to care, treatment R&D

- **European Federation of Pharmaceutical Industries and Associations**
  - Collaborates (e.g. through European Vaccine Manufacturers group) with patient groups to support public health programmes and access to care.
  - Elaborated Code of Practice to collaborate with patient organizations, to ensure ethical conduct and transparency
National Viral Hepatitis Roundtable (USA)

- Aim: to develop, implement and maintain a national strategy to eliminate viral hepatitis in the USA
- Broad membership (>100 member organizations at national level)
- Formulated plan: “Eliminating Hepatitis: A Call To Action” (at high cost); delivered to Congress
- Acts as national coalition of organizations
- Disseminates information on policy issues
- Collaborates among others with Centers for Disease Control and Prevention in work on priority setting
Questions of terminology

• Europe (EU, EC, WHO European Region; ECDC, "Europe must lead …")
• Patient-centred
• Patient-driven
• Patient organization
• Patient (including relatives)
• Prevention (primary, secondary)
• Challenge
Patient organizations - objectives

• Range from narrow focus on patients' welfare and support, and on one condition, to broad activities covering all liver diseases (including non-viral conditions) and immunization generally
• Prevention
• Counselling
• Information dissemination (including educating general practitioners)
• Increasing public awareness
• Lobbying
• Coordination of other groups
• Research (identification of needs, support and funding)
Patient organizations - structure

- Range from small groups of volunteers and a few paid professionals to full membership organizations with assemblies, boards, directors, advisors, trustees
- Membership with fees to traditional association
- Formal traditional decision-making processes to innovative e-governance to small independent bodies
- Funding: fees, fund-raising activities, donors, pharmaceutical industry, government support; grants: EURORDIS limits funding from pharmaceutical industry to 20%
Patient organizations - services and activities

- Target audiences: similar range, from individuals (including people at risk, prisoners and war veterans) to national and professional bodies
- Networking, online forums, chat forums
- Informational ("inform, inform and inform") and educational (multimedia: print, electronic)
- Toll-free telephones
- Surveys of perception
- Campaigns, talks in schools
- Conferences
- Counselling centres
Patient organizations - services and activities (continued)

• Media work
  – Including PR campaigns (including restoration of funding for treatment)
  – World Hepatitis Day, national liver days
• Lobbying
  – Policy and parliamentarians
  – Legislative proposals
  – For vaccines, vaccination programmes, and their funding (free, reimbursement, …)
• Medical and professional information and awareness
  – General practitioners
  – Health-care workers (prevention of occupational exposure)
  – Conferences
• Guidelines (for medical profession and public, e.g. on tattoos)
• Screening campaigns
Patient organizations - weaknesses/obstacles

- Lack of/limited funds or governmental support; competition for scarce resources
- Lack of staff; reliance on volunteers
- Performance: perception as "amateur"; need for training and evaluation
- Lack of clearinghouse function to raise awareness of existence of other groups, foster communication between them and stakeholders (e.g. health insurance bodies)
- Prejudice and stigmatization remain ("dirty diseases", "incurable"; "isolate people infected with hepatitis C")
- Lack of high profile lobby (as for HIV/AIDS, breast cancer), and need to counter stigmatization
- No presence or representation in technical agencies
- Information available in only one language; language and cultural barriers
- Segmented work portfolio of some organizations, but need to reach out to vulnerable populations
- Perceptions/misperceptions about the role of pharmaceutical industry
- Some media not supportive and reinforce negative messages
- Anti-vaccination lobby/mis- or dis-information
Patient organizations - weaknesses/obstacles (continued)

- No comprehensive, national prevention programme, or lack of implementation of plans; no hepatitis B vaccination programme
- Lack of good epidemiological data on hepatitis B and hepatitis C virus infections/disease
- Misconceptions about routes of transmission
- Unawareness of most people infected with hepatitis C virus of fact that they are infected; limited funds for diagnosis and treatment
- Insufficient knowledge about hepatitis B and hepatitis C, including that of health-care workers (leading to breaches of infection control)
- Little evidence of cost-effectiveness of screening/treatments; need to produce screening and practice guidelines
- Low interest levels among decision-makers
- Collaboration with official health institutions difficult; resistance (jealousy of patient organizations) in governmental institutions
- Politics, changes in government, collaboration between patient organizations
- Role of civil society
Patient organizations – strengths

• Ability to get message across: information dissemination in various means (web sites, newsletters, …); information seen as easy to understand, accurate, unified; public resources of information; online forums for discussion, chat
• Ability to network more easily than bureaucracies and other groups
• Message and language can be adapted to target patient groups
• Multilingualism – working in many languages, especially those of some hard-to-reach groups (immigrants)
• Cultural sensitivity
• Broad support from: professional bodies/associations; parliamentarians
• Media support, trust and respect – part of a broader set of qualities:
  – uniqueness, legitimacy, trust, dedication and energy, positive image, common purpose, access to specialists
• Free or relatively inexpensive resource: doing governments' job cheaper, and filling gaps in governments' health programmes
• Ability to audit and monitor various activities (policy, guidelines, treatment protocols, etc)
• Social support in preventing serious disease
Patient organizations – strengths (continued)

- Ability to operate at national level
- Partnerships/umbrella organizations
- Professional teams/strong links with professionals
- Input into policy-making and decision-taking processes
- Neutral status (including between doctor and patient)
- Capitalizing on/contributing to civil society
- Ability to report breaches of good practice that encourage transmission of hepatitis C virus
- In countries where alcohol-related problems are a high priority, focus on alcohol might offer a springboard for advocacy of viral liver disease
Patient organizations - achievements

• Successfully gained reimbursement of costs
• Increased awareness (incl. through use of media, high-profile innovative campaigns (Asian Liver Center's Jade Ribbon Campaign) etc)
• Paved way to changes in laws/legislation
• Setting gold standard for treatment of hepatitis C virus infection
• Contribution to introduction of vaccination of newborns against hepatitis B
• Contribution to a decreased disease burden/prevalence of hepatitis B and hepatitis C
• Contribution to destigmatization/increase in human rights of patients
• Organization of free testing, screening
• Promoting vaccination against hepatitis B in people infected with hepatitis C virus
• Cultural and immigrant outreach
Challenges for the future

- Introduction of legislation, implementation of programmes (funding sources - government, pharmaceutical industry); advocacy for implementation of national plans
- Information: clear and consistent message essential
- Outreach: hard to reach populations (injecting drug users, immigrants, especially in appropriate languages): hepatitis B patients harder to reach than hepatitis C patients
- Development assistance in health sector (west Balkans)
- Need to promote and awareness generally at all levels and World Hepatitis Day
- Cooperation and partnership during European Immunization Week
- How to increase awareness/knowledge of health-care workers
- How to improve quality of epidemiological data
- Continued expansion of activities across borders, between countries (e.g. Germany and Turkey)
- Evaluation of impact
- VHPB to consider endorsement of World Hepatitis Day
- VHPB seriously considering offering a seat on its Board to an ELPA member
Opportunities

• Time to "finish the job" of hepatitis B vaccination
• Using influence to persuade governments that there are good economic reasons to introduce interventions (screening, …)
• Potential for greater involvement in primary prevention, data collection, consistent approach to development of guidelines, synergistic work with specialists
• Patient organizations are well placed to reach vulnerable populations
• Opportunity to improve quality of life through quality of care
• Ensure equality of access to prevention and care
• Raise profile of the need for a healthy liver and hepatitis; place for a global viral hepatitis initiative