



PROGRESS ACHIEVED IN HEPATITIS PREVENTION AND CONTROL IN TURKEY ROLE OF NGO'S

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- **Non Governemental Organizations play an important role in their efforts to empower patients and their families.**
- **They endorse a major responsibility in eliciting awareness in the Society against viral hepatitis and their potential complications,**
- **They constitute a bridge between the infected or under threat population and the national health organisations**

- ① **Participants gain increased knowledge from speakers, facilitators and other patients.**
- ② **Patients develop and improve coping skills.**
- ③ **They also acquire increased confidence and acceptance of their liver disease through the knowledge that they share a common struggle.**

Associations and umbrella organizations

- **Viral Hepatitis Prevention Board (VHPB)**
- **European Liver Patient Association's (ELPA)**
- **European patient groups for rare diseases**
- **(EURORDIS)**
- **European Federation of Pharmaceutical Industries and Associations (EFPIA)**
- **National Viral Hepatitis Round Table**

ELPA

- ELPA represents 20 patient groups out of 17 EC
- Aim is to promote the interests of people with liver disease,
 - Raise awareness and promote prevention
 - Promote well-defined targeted screening of viral hepatitis across Europe
 - Address the low profile of liver disease as compared to other areas of medicine such as heart disease
 - Share experience of successful initiatives
 - Work with professional bodies such as the EASL and with the EU to ensure that treatment and care are harmonised across Europe to the highest standards
 - Coordinate campaigns with uniform messages across Europe

PATIENT AND ADVOCACY GROUPS

- **Belgium:**
Carrefour Hépatites-Aide et Contact (CHAC)/
- **Bulgaria:**
Bulgarian National Association for fighting HEpatitis (HEPASIST) .
- **Croatia:**
Croatian Association of Treated and Ill with Hepatitis (HEPATOS)
- **Germany:**
Deutsche Leberhilfe .
- **Italy:**
EpaC
- **Poland:**
HCV Patients Association
PROMETEUSZE
- **The Netherlands:**
National Hepatitis Centre (NHC)
- **UK:**
British Liver Trust (BLT) .
- **US:**
The Hepatitis Foundation International (HFI)
- Advocating for immigrant communities at risk:
- **Asian Liver Centre (ALC) .**



Teamwork and leadership is essential

IN TURKEY

PATIENTS ORGANISATIONS EXIST FOR:

- Ankylosing spondilitis
- Hemophilia
- Autistic Children
- Mentally and physically handicapped people
- Osteoporosis
- Celiac Disease
- Inflammatory Bowel Disease
- Multiple Sclerosis
- Diabetes
- Obesity

But there is no such a society for
viral hepatitis patients !!

The reason for the lack of effective patient's leagues against viral hepatitis are

- **Social stigma** (☹ defined as a strong feeling of rejection, insecurity, shame or social isolation)
Patients never wish their disease to be identified by their relatives, friends and partners
There is a misbelief that hepatitis is acquired by **immoral behaviours** and it is **the responsibility of the individual to get the disease**
Stigmatisation is especially valid for HCV patients

⦿ **Fear of losing job or position**

- Some companies do not accept to work with Hep B or hep C patients even though they have inactive disease
- These people are not allowed to swimming pools, baths or other public places

⦿ **Lack of awareness** in the society for these particular diseases and their transmission routes

⦿ **Physicians attitude** towards the problem

⦿ **Role of Media:** Seek for popularity and concern for rating

Societies, Foundations, Advocacy Groups and interests groups for viral hepatitis in Turkey

- Turkish Association for the Study of the Liver (TASL) 1992)
- Turkish Liver Foundation TKV (1992)
- Turkish Society of Gastroenterology TGD (1959)
- Society for Fight against Viral Hepatitis (VHSD) 1989
- Infectious Diseases and Clinical Microbiology Specialty Society (ECMUD) 2006
- Turkish Liver Transplantation Society TKTD(2005)
- Liver Transplant Patients Society (2008)

Activities of the Liver Associations and Viral Hepatitis Societies in Turkey

1. **Educational Activities** (*Seminars, Congresses, Short Courses, Schools, Symposia, CME and PG Education*)
2. **Public Awareness Activities** (*Conferences, Forum Discussions, Interactive Sessions, Media & TV sessions*)
3. **Field Studies** (*Screening, testing, consulting, educating people, advising them to get vaccinated*)
4. **Elaboration and diffusion of educational material** (*booklets, brochures, leaflets, posters, books*)
5. **Consultancy to MoH for prevention, diagnosis and management of viral hepatitis**



Turkish Association for the Study of the Liver (TASL)

- Founded in 1992
- Has 390 members
- Liaisons with EASL, APASL and similar societies
- Organized EASL PG Course (1998) and Annual Meeting (2003) and contributed to many International Meetings
- Member of the Boards for Hepatology Education within Gastroenterology Training in Europe and Asia

Mission and Vision of TASL

- To promote reseach in liver diseases,
- To spread information about recent advances in hepatology
- To educate health professionals about liver diseases and notably viral hepatitis
- To increase the awareness of the population about liver diseases in Turkey
- To foster preventive measures concerning viral hepatitis and related diseases

Vision

- To become a stronger and more influential Society in preventive and therapeutic hepatology and play the role of major partner in health policies related to Liver diseases
- The official journal of TASL to become indexed in SCI
- To contribute to the eradication of HBV by universal vaccination campaign led by MoH and societies

What did we achieve so far ?

- 4 major activities deserve to be mentioned:
Education, Research, Scholarships and Social Responsibility Projects
- **Grants** and **Awards were given** to young investigators who pursue abroad research for short or long term about liver diseases and especially viral hepatitis
- **Educational** material were elaborated for the public and our colleagues, Articles in major newspapers, books , leaflets, newspaper articles

- TV programmes in special days to raise public awareness on VH (ex. May 19 th “World hepatitis day” proclaimed by WHO, before the opening of schools, at summer time etc..) This years’ motto was “get tested” as announced. Will be next year “Get treated !
- Active web page corresponding with members and people who seek advice in LD and hepatitis
- Elaboration and Publication of **Guidelines** in HBV and HCV management
- Consultancy to MoH in the subject of **hepatitis and other liver diseases** management

- ◎ **National Hepatology Meeting and School of Hepatology** occurring in alternate years
- ◎ **Monthly PG** courses, pannels or seminars mostly focusing on VH and related complications
- ◎ **Publication** of “Hepatology Forum” a journal devoted to liver diseases
- ◎ **Participation** to EU grants dedicated to Viral hepatitis

Epidemiology of Viral hepatitis

- Turkey is situated in a region of intermediate HBV prevalence.
- HbsAg seropositivity ranges from 3.1% to 10.4% ,anti-HBs seropositivity ranges from 19.8 % to 50%.
- Overall HbsAg and anti-HBs seropositivity rates are 6.1% and 34.6% respectively in adult population
- Anti-HCV positivity is 0.6%-1 % in Turkey.
- The prevalence of HDV among HBV positive subjects in Turkey ranges from 2.1% to 74%.

- In Turkey, a population based study was needed in order to assess the prevalence of different types of hepatitis and to adopt effective strategies in prevention and management of hepatitides

Population based study on the prevalence of Viral hepatitis in Turkey

- Launched in 2008 with a budget of 550.000 USD
- Address Based Population Registration System (ABPRS) completed in 2007 and was used for a 2-stage systematic cluster sampling method.
- 5250 people in 24 Cities selected according to Eurostat were screened randomly by home visits ,and HBV (HDV when +ve) HCV,HAV were tested in blood samples obtained
- Results will be available by End-November

Future Projections

- ⦿ More effective **awareness and education** campaign in collaboration with Society members, interests groups, colleagues, other NGO's , health authorities ,Stakeholders and Institutions as well as media partners
- ⦿ **Primary care centers** and **advocacy groups** impact
- ⦿ Effort to raise the **gouvernement's interest** in order to adopt more effective policies to combat the viruses
- ⦿ Get into closer contact **with EU and European Parliament** to promote the campaign throughout the country
- ⦿ Raise **funds for research**, from internal and external resources

Activities of other societies

(Society for fight against Viral hepatitis (VHSD))

- A two years Ambulatory Hepatitis Screening project via “yellow bus”.
- In collaboration with MoH
- The motto is “**get tested**”. More than 10 cities in East and Southeast Anatolia visited. Still continues.
- Tests were done and advice for vaccine given to citizens. Vaccine provided by MoH if needed



Türkiye'de Aşılama
üzünde güllü **Haydi!**
faydası var.

Delanterisi, helikol

Haydi gelin!
Bilgilenin, Korunun, Test Yaptırın, Aşılının.

Haydi gelin!
Bilgilenin, Korunun, Test Yaptırın, Aşılının.

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Haydi gelin!

Bilgilenin, Korunun, Test Yaptırın, Aşılının.



www.ahad.org
0212 433 74 26

0212 337 11 25



www.nhrc.org

Türkiye'de 4 milyonun üzerinde gizli Hepatit taşıyıcısı var. Onlardan biri, belki de sensin!

Haydi gelin!

Konuşun, Test olun, Tedavi olun!



Doç. Dr. Mustafa Erkin

NHRC Başkanı

Prof. Dr. Ferid Berk

NHRC Başkanı

NHRC Başkanı



Posters about the bug on the buses, Billboards and public places

Video demonstration in public halls ! Clips before movies, TV strips , short programmes etc..

Campaign sponsored by BMI



“It’s not responding to medication, so the next step is to bring legal action against the virus.”

Recently established

- Patients organisation (Society) by Turkish Liver Foundation (Prof.Gürakar)
- Transplanted people's Society

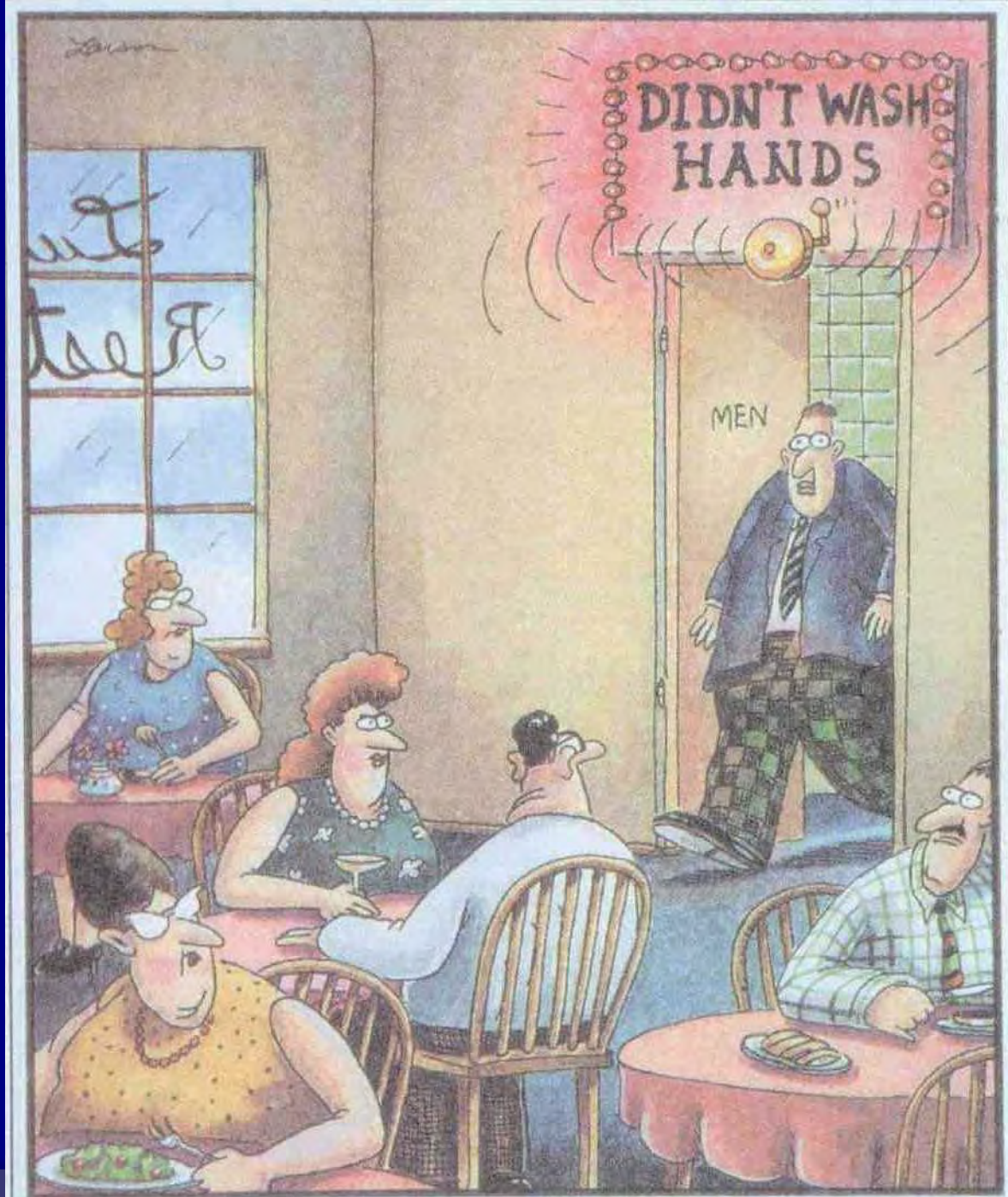
CONCLUSION

- Non Governmental Organizations (NGO) have an important role in developing and implementing policies about the prevention of viral hepatitis ,
- They endorse considerable responsibility in the education of the professionals and the public , to raise awareness as well as funds for research and management

- ⦿ However, the majority of the active NGOs in Turkey and elsewhere suffer from the scarcity of financial capacity and efficient communication networks
- ⦿ “Old concepts die hard”
- ⦿ More work is needed to define specific goals and the ways of action
- ⦿ More solid epidemiological data is needed in Turkey and in Europe especially in immigrants and special groups (prisoners, IVDU)

***“Intellectuals solve problems;
geniuses prevent them.”***

Albert Einstein



- ⦿ Money won't buy happiness, but it will pay the salaries of a large research staff to study the problem.
- ⦿

Bill Vaughan

