ASOCIATIA ROMANA ANTI-SIDA

Membră a Coaliției Internaționale Sida PLUS

Carusel

APAH-RO
Asociația Pacienților cu Afecțiuni Hepatice din România

PREVENTION AND CONTROL ACTIVITIES BY CIVIL SOCIETY AND PATIENT ORGANIZATIONS

Marinela Debu (APAH-RO),
Marian Ursan (Carusel),
Maria Georgescu (ARAS)

ELIMINATE ~~HEPATITIS~~

NOhep

Bucharest, 17 May, 2018

ABOUT APAH-RO/ ARAS/ CARUSEL

- The Romanian Liver Patients Association (APAH-RO) was established in 2009, by a group of patients affected by liver disease, currently with branches & regional centers in Alexandria, Arad, Brasov, Bucharest, Iasi and Cluj
- APAH-RO aims to raise awareness on viral hepatitis key issues such as: access to treatment for all patients, without discrimination; prevention, without disruption – vaccine for Hepatitis B
- APAH-RO is a member of ELPA, WHA and APCR

- ARAS – the Romanian Association Against AIDS was founded in 1992 and ever since, we have been fighting for the patients' rights, by elaborating and implementing the first AIDS National Strategy and by being continuously advocating for access to prevention, testing and treatment
- ARAS is the first NGO working in harm reduction and, as such, we discovered an important number of people living with HIV, Hepatitis B/C and, later on, TB; as such, we have played an important role in the linkage to care for vulnerable populations
- ARAS is a member of Coalition Plus, AIDS ACTION EUROPE and of the Country Coordination Mechanism for the Global Fund Implementation in Romania

- CARUSEL aims to improve the quality of life for drug and alcohol users, sex workers or individuals who have multiple sex partners, persons who live on the streets, socially and economically challenged people end the ones that are at risk of getting sick or facing social exclusion.

HEPATITIS,
STATE OF PLAY IN ROMANIA

Viral hepatitis – a public health issue

~ 600.000 Romanians live with chronic hepatitis C!

~ 800.000 Romanians live with chronic hepatitis B!

Increase in reported hepatitis A and E cases!

~ 85% of the injecting drug users diagnosed with HIV also have Hep C!!

ROMANIA RANKS 4TH, IN EUROPE, IN TERMS OF LIVER DISEASE DEATHS!

Romania is among the countries that do not have specific policies for prevention, diagnosis and treatment targeting viral hepatitis!

Past efforts in addressing the issue were mainly inconsistent!

CHALLENGES IN ADDRESSING VIRAL HEPATITIS

- According to Euro Hepatitis Care Index* (2012), the main issues in terms of viral hepatitis in Romania include:
  - Lack of systematic measures for diagnosis
  - Lack of financing for testing without a recommendation from the GP or from a specialist doctor
  - Lack of a national register for Hepatocellular Carcinoma (HCC)
  - Lack of specialized medical assistants dedicated to viral hepatitis
  - Lack of a national efficient system for monitoring viral hepatitis

* http://www.healthpowerhouse.com/files/euro-hepatitis-index-2012/Report-Hepl-HCP-121104-2-w-Cover.pdf

ROMANIA/ ACCESS TO TREATMENT

2009 – 2011

- 2009: APAH-RO is established
- During this time, we focused on raising awareness in regards to eliminating waiting lists for access to treatment with interferon and ribavirin

2012 – 2014

- Triple therapy

2015

- There were initiated discussions for access to innovative treatment (DAA) for patients with Hepatitis C
- November 2015: the Therapeutic protocol was published

2017

The DAA cost-volume-result contracts continued for the Hepatitis C treatment

- Discontinuity in securing the vaccine for Hepatitis B (included in the mandatory vaccination schedule)

2018

- Analysis/ tests for viral hepatitis (diagnosis & monitoring) reimbursed by the National Health Insurance House were included in the basic analysis package prescriped by GPs – starting April 1st, 2018
- THERE MIGHT BE DELAYS FOR THE NEW COST-VOLUME-RESULT CONTRACT (hepatitis C treatment)
- The Ministry of Health announced the launch of a screening program (hepatitis included)
- Under discussions: Prevention Law and the new Healthcare Law
- Work in progress for the National Healthcare Strategy
- Ambulatory services – free of charge analysis: viremia and fibroscan

HEPATITIS C/ PATIENTS TREATED

- Since 2015, **over 18.000 Romanian patients** benefited of the interferon free therapy
- APAH-RO advocates **for the inclusion**, within the program supported by the National Health Insurance House, **of F1 and F2 patients**
  - Healthcare personnel has access to the interferon free therapy without being conditioned by the fibrosis stage

VIRAL HEPATITIS…
LOOKING FOR ANSWERS TO SPECIFIC SITUATIONS

- In terms of regulations, Romania looks to be on the right path
  - **However, there are important milestones to overcome when talking about implementing those regulations that should help patients in terms of diagnosis, treatment and monitoring**
- Fibroscan is not available in some specialized hospitals (infectious/ gastro) because the management cannot afford this investment – HOW CAN THIS ISSUE BE ADDRESSED IN THE BENEFIT OF THE PATIENTS?
- Screening & treating people at risk (uninsured, without identity papers)- drug users, homeless people, people living in secluded areas with limited access to medical services
  - Authorities should take into consideration a system to ensure everyone's right to healthcare services, especially when talking about infectious diseases
- **Analysis/ tests for viral hepatitis (diagnosis & monitoring) reimbursed by the National Health Insurance House were included in the** basic analysis package prescriped by GPs
  - **In reality, at this point the system is not functional**

VIRAL HEPATITIS…
LOOKING FOR ANSWERS TO SPECIFIC SITUATIONS

- In secluded areas, with limited access to medical services & population heavily affected by poverty, there should be considered securing the testing services at the GPs' cabinets, in collaboration with analysis laboratories
- Social stigma – employers need to ensure the right to privacy & the right to work
  - **Labor Code does not have special provisions regarding discrimination based on the healthcare condition of the employee**

ACTION POINTS FOR ROMANIA
VIRAL HEPATITIS

Acknowledging hepatitis as a PUBLIC HEALTH ISSUE!

- Implementing a NATIONAL PROGRAM FOR VIRAL HEPATITIS -

Securing a framework targeting a wide range of people at risk: people that do not have medical insurance, people who inject drugs, prisoners etc.

PROGRAMS FOR RAISING AWARENESS & PREVENTION

SCREENING (diagnosis at early stages)

- Increasing chances of getting cured
- Decreasing the risk of spreading the infection
- Decreasing treatment costs related to complications – cirrhosis, liver cancer

ACCESS TO TREATMENT

Treating infection at an early stage reduces costs related to treating complications!

National Register for Hepatitis!

MONITORING

- Reimbursing analysis/ tests
- Securing psychological counseling

ACTION POINTS FOR ROMANIA
HEPATITIS C

APAH-RO supports **the following proposals aimed at increasing patients' access to treatment & securing better pricing within negotiations:**

1. Implementing a **MULTI-WINNER SYSTEM,** in order to eliminate discrimination in terms of access to treatment for certain categories of patients

2. **LONG-TERM CONTRACTS** (more than a year), in order to ensure predictability in regards to access to treatment

3. **INITIATING THE PROCEDURE FOR NEGOTIATIONS IN DUE TIME,** in order to avoid disruptions in terms of access to treatment for patients

- In line with the European guidelines, access to treatment **without discrimination** (regardless of the fibrosis status)
- **Increasing the number of patients treated**
- Identifying **solutions for people that do not have medical insurance**
- Interferon free **treatment for transplant patients**

ASOCIATIA ROMANA ANTI-SIDA

Membră a Coaliției Internaționale Sida Plus

Carusel

APAH-RO

Asociația Pacienților cu Afecțiuni Hepatice din România

Contact:

President: Marinela Debu
E-mail: hepatobv@gmail.com, roapah@gmail.com
Mobile: +40 721 304 160
www.hepato.ro