



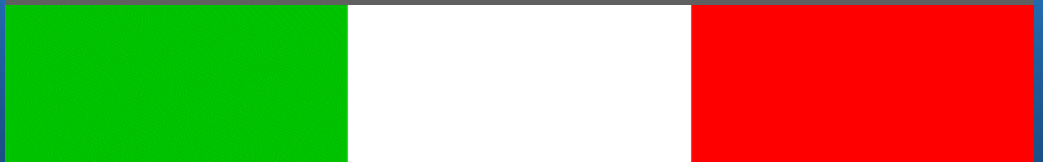
Lucca  
March 13th-14th 2008

Prevention and  
control of viral  
hepatitis:  
Role and impact of  
liver patient groups in  
Europe.

**EpaC**

**EpaC**   
Associazione Onlus  
Educazione  
Prevenzione  
Ricerca  
sull'Epatite C

italy



**EpaC has been founded  
in 1999**

**By two patients**

because at that time there were no free  
informations available for patients about HVC  
in Italian language

**INFORM** THE GENERAL POPULATION

TAILORED **COUNSELLING** FOR PATIENTS  
AND THEIR FAMILY

**EDUCATE** THE FAMILY DOCTORS

FINANCE **RESEARCH** PROJCECTS

## **PATIENTS TAKE CARE POLICY**

**PERSONALIZED AND TAILORED  
INFORMATIVE ASSISTANCE**

**ACCOMPANY PATIENTS DURING  
THE “*VIRUS FREE*” LONG RUN STEPS**

**IN ANY CASE IMPROVE PATIENT QUALITY OF  
LIFE**

## **ACTION TAKEN FOR EACH SINGLE PATIENT**

**GET IN TOUCH WITH THE PATIENT**



**SEND HIM TO A PROFESSIONAL HEPATOLOGIST**



**SUPPORT ABOUT THE RIGHT WAY UNDERTAKEN**



**STABILIZE HIM AS MUCH POSSIBLE**



**SUPPORT HIM DURING THE THERAPY**

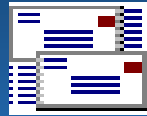


**MOTIVATE HIM IN CASE OF THERAPY FAILURE**

# HOW AND HOW MUCH ?



By telephon



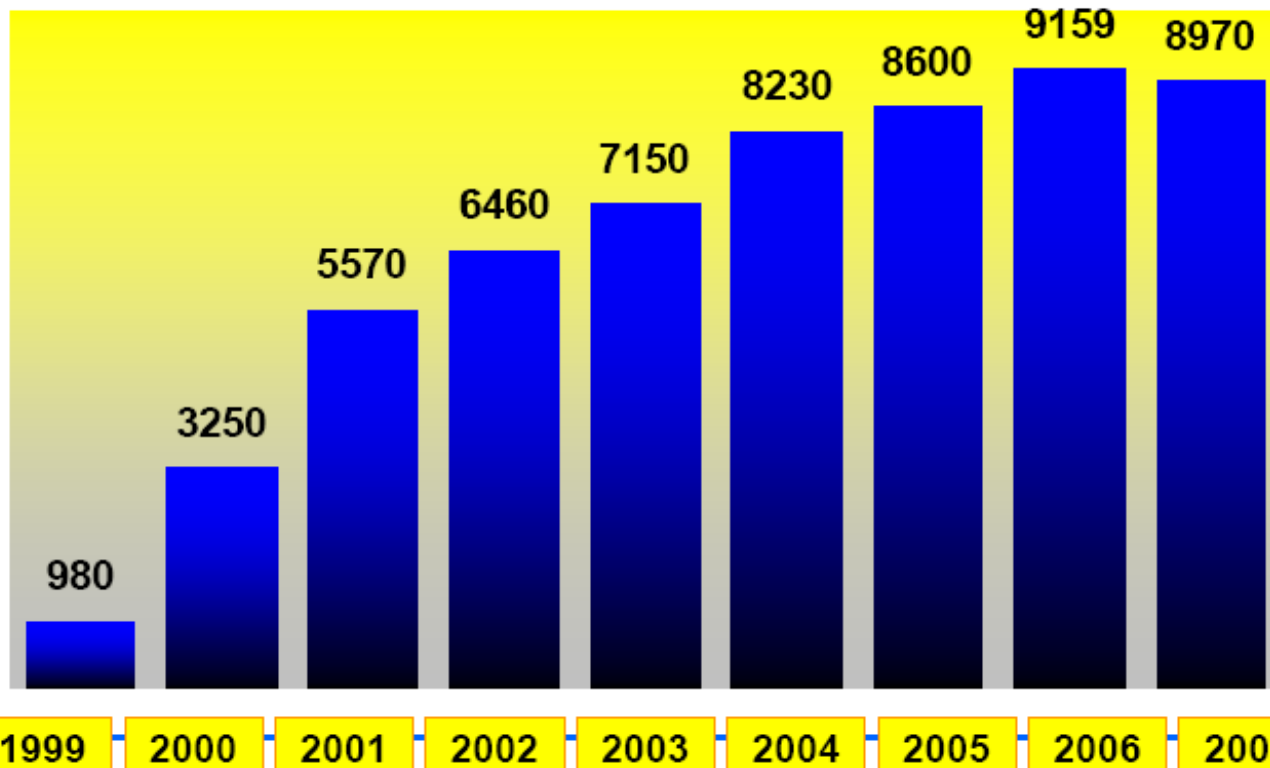
email



Ad personam



Self help groups



YEARLY  
REQUEST  
COUNSELLING





## STRUCTURE

### MILAN OFFICE

**Full/time President**  
**Full/time Vice President**  
**Full/time Fund raiser**  
**Full/time Website responsible**

**5 regional contact persons**

**10 collaborators**

**15 Volunteers**

**Scientific Committee**

**2 lawyers**

**1 Nutritionist**

**Other professionals**

### ROME OFFICE



## **PECULIARITY**

**MILAN OFFICE**

**MANAGED 100% BY PATIENTS**

**NO DOCTORS INSIDE  
ONLY EXTERNAL SUPPORT**

**ROME OFFICE**

**STEERING COMMITTEE COMPONENTS  
ARE ALL PATIENTS WITH  
CIRROSHIS, LIVER TUMOR OR  
TRASNSPLANTED**



## PERSONNEL

### MILAN OFFICE



**EMPLOYED FULL TIME**

**03**

**EMPLOYED LIMITED  
CONTRACT**

**02**

**VOLUNTEER  
REIMBURSED**

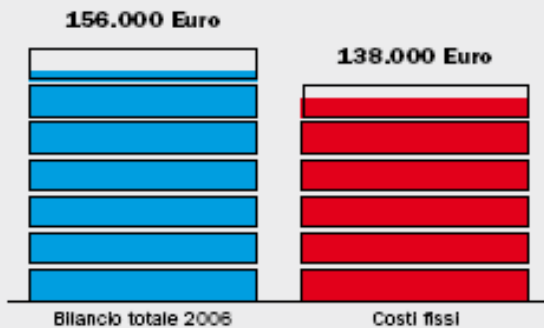
**10/15**

### ROME OFFICE



# BUDGET 2006

## Entrate



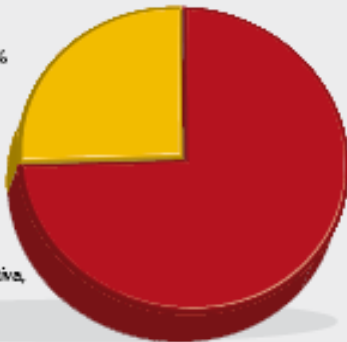
**Fixed costs**

**138.000 Eu**

## Utilizzo Fondi

Per Struttura/  
Amministrazione 26%  
Fitti, telefonia  
e cancelleria 2 sedi

Per Mission 74%  
Personale, consulenze,  
trasferite, attività divulgative,  
sito internet, ecc.

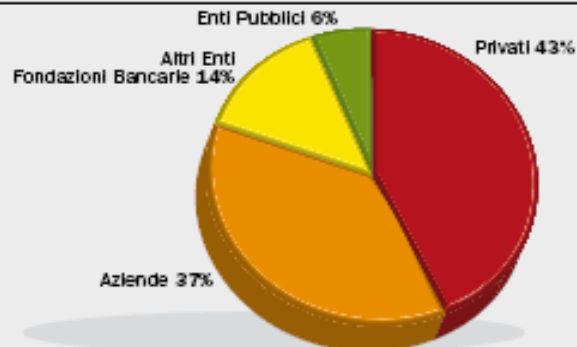


**utilization**

**26% structure**

**74% mission**

## Provenienza entrate



**sources**

**43% supporters**

**37% companies**

**20% other sources**

**5**

**Steering Committee  
members**

**Take decisions 3 times yearly,  
Assembly is validated via chatline**

**21**

**assembly members  
Can vote**

**Assembly  
via chatline  
Once year**

**7500**

**Supporters  
No decision vote**

**Constant  
informations**

**30.000 SUBSCRIBERS TO THE MONTHLY NEWSLETTER BY MAIL**

## TOOLS

## TARGET AUDIENCE

**POPULATION: 55 milion**

**Massmedia,  
newspapers,  
internet, TV  
spot, depliants**



**PATIENTS: 2 milion**

**Newsletters,  
informative  
brochures,  
video, ecc.**



**Family DOCTORS: 55.000**

**Internet and  
Professional  
manuals**



reached

**POPULATION: 55 milion**

In 10 years reached 25 milion  
people with our caimpaign

**Reached 50%**

**PATIENTS: 2 milion**

Our webiste has been visited  
by 1.500.000 people

**Reached 40-60%**

**Family DOCTORS: 55.000**

Distributed 10.000  
professional brochures

**Reached 20%**

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TAILORED **COUNSELLING** FOR PATIENTS AND  
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# INFORM GENERAL POPULATION



**5 National  
Awarines  
campaign**

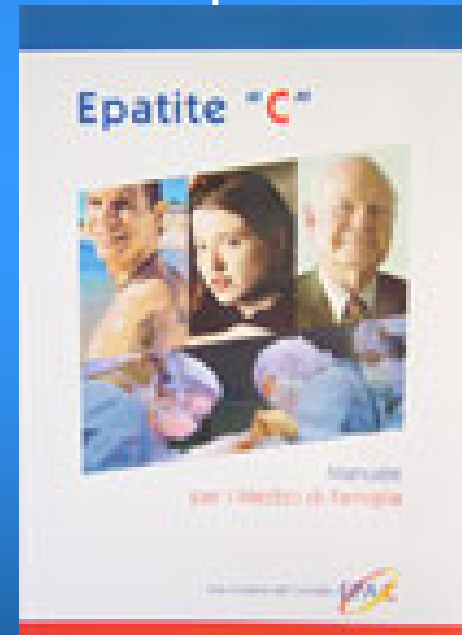
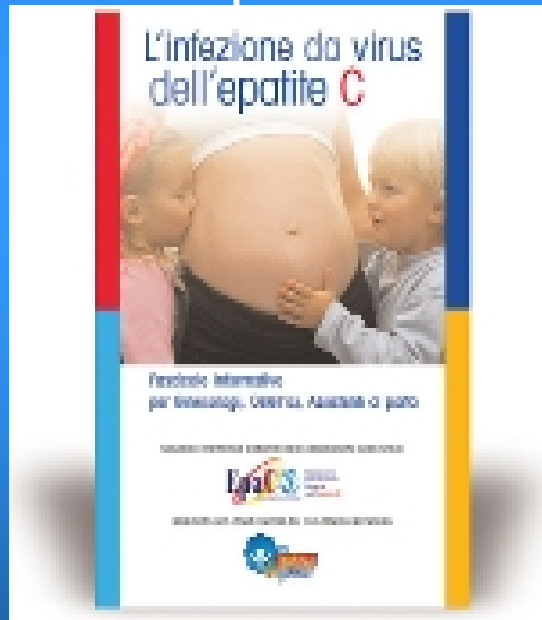
# INFORMATION ACTIVITY FOR PATIENTS AND THEIR FAMILY



COOPERATION WITH ITALIAN ASSOCIATION STUDY OF THE LIVER



# EDUCATION TO THE FAMILY DOCTORS



# MORE THAN **130.000** Euros donated for **RESEARCH** projects



Investigation  
on Mother to  
newborn  
vertical  
transmission

**Padua**



New database  
transplanted

**Turin**



epidemiologic  
Database  
of children  
infected HCV

**Padua**



Publications of  
pediatric and  
ginecologist  
guidelines on  
HCV

**Padua**

# LOBBYING ACTIVITY



**PETITION TO THE  
ITALIAN MINISTRY  
OF HEALTH**

**LAW PROPOSAL ON  
HEPATITIS S.1457**

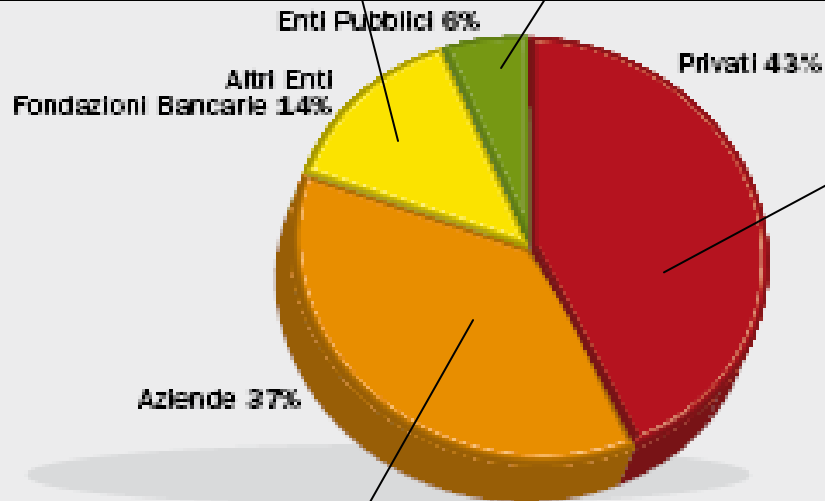
**MANIFESTATION IN  
FRONT OF ITALIAN  
PARLIAMENT**

**MEET EU ITALIAN  
POLITICIANS**

**Foundations  
14%**

**Public institution  
6%**

**Provenienza entrate**



**Members and  
supporters  
43%**

**Pharmaceutical  
Companies  
37%**

## OTHER LIVER RELATED ASSOCIATIONS

**MOST IMPORTANT IS  
LIVER-POOL**



**ITALIAN FEDERATION OF LIVER PATIENT ASSOCIATIONS  
WITH MORE THAN 15 ASSOCIATIONS**

## STRENGTHS

WE ARE THE MOST **KNOWN, RESPECTED AND BIGGER** ASSOCIATION OF LIVER PATIENT IN ITALY

WE ARE A **PUBLIC RESOURCES**, BECAUSE NOBODY ELSE CAN HAVE THE QUANTITY AND QUALITY OF EPIDEMIOLOGIC INFORMATIONS WE COLLECT EACH DAY

WE FOCUS ON PATIENT QUALITY OF LIFE AND

WE LOVE PATIENTS BECAUSE WE ARE PATIENTS AS FIRST

WE CAN MOVE PEOPLE ON ***“DO SOMETHING ABOUT”***

**LOT OF RESISTANCE FROM SOME POWERFUL PEOPLE  
INSIDE HEALTHY GOVERNMENT INSTITUTIONS**

**USUALLY THEY CLAIMS:**

**THERE ARE NOT ENOUGH EVIDENCES OF **COST/EFFECTIVENES**  
OF SCREENING AND TREATMENTS**

**THERE ARE NOT ENOUGH EVIDENCES OF **COST/EFFECTIVENES**  
FOR AWARENESS CAMPAIGN ON HEPATITIS**

## CONCLUSIONS – KEY POINTS

**HEPATITIS PROBLEM IS VERY EXPENSIVE AND ALLARMISTIC FOR POPULATION**

**GOVERNMENTS HAVE FEAR TO FACE WITH ANOTHER  
“AIDS” SITUATION AND PREFER BE SILENT**

**PATIENT ASSOCIATION ON A VOLUNTEER BASE MAKE A GOOD  
JOB BUT ARE NOT DETERMINANT FOR BIG PURPOSES.**

**THEY HAVE NO MONEY, NO INTERNAL QUALIFIED PERSONEL, NO  
STRUCTURE.**

**PATIENT ASSOCIATIONS MUST BE INDEPENDENT, 100% IN THE  
HAND OF PATIENTS, FULL TIME EMPLOYED, WITH FUNDRAISING  
ACTIVITY AND WORK TO GET MORE AND ORE MEMBERS AND  
GIVE A SERVICES OF PUBLIC UTILITY**