



# **EUROPLAN PROJECT**

## **NATIONAL CONFERENCE ON RARE DISEASES**

### **WORKSHOP**

### **PATIENT EMPOWERMENT AND SPECIALISED SERVICES**



**RELEVANT EXTRACT FROM THE  
EUROPEAN COUNCIL RECOMMENDATIONS  
ON ACTIONS IN THE FIELD OF RARE DISEASES**

**LUXEMBOURG, 9 June 2009**

# COUNCIL RECOMMENDATIONS

**“HEREBY RECOMMENDS that Member States:**

- **Consult patients and patients' representatives on the policies in the field of rare diseases and facilitate patient access to updated information on rare diseases.**
- **Promote the activities performed by patient organisations, such as awareness-raising, capacity-building and training, exchange of information and best practices, networking and outreach to very isolated patients.”**



**RELEVANT EXTRACT FROM THE  
SPECIFIC EUROPLAN RECOMMENDATIONS  
FOR THE DEVELOPMENT OF NATIONAL PLANS  
FOR RARE DISEASES**

# EUROPLAN RECOMMENDATIONS

- Advocacy of patients' needs by patients' associations is recognised as an important element in defining policies on rare diseases; the organisation of a national umbrella organisation that represents the interests of all rare diseases patients is encouraged
- The patients' organisations are involved in decisions making processes in the field of rare diseases
- Valid information on rare diseases is produced and made available at national level in a format adapted to the needs of patients and their families. Information to patients is available on the EURORDIS website in six languages, till now; information given on Orphanet websites is also translated into several EU languages
- Specialised social services are supported for people living with a chronically debilitating rare disease and their family carers

# EUROPLAN RECOMMENDATIONS

- Specialised social services are established to facilitate integration of patients at schools and workplaces
- A directory of centres providing specialised social services, including those offered by patients' associations, is compiled, kept updated and communicated to national, regional and patients' websites and included in the Rapsody network
- National help lines for patients are supported, advertised and linked to the Network of Rare Disease Help lines (Rapsody Project)
- Information and education material is developed for specific target groups (e.g. teachers, social workers, etc.)
- Facilitate the activities aiming at patients' empowerment carried out by patients' associations



**RELEVANT EXTRACT FROM THE  
EUROPLAN INDICATORS  
TO EVALUATE THE ACHIEVEMENTS OF RD INITIATIVES**

# EUROPLAN INDICATORS FOR PATIENTS' EMPOWERMENT

ACTIONS	INDICATORS	TYPE	ANSWERS
Promoting the existence of a RD patients' organisation that represents all RD patients' associations	Number of umbrella organisations specific on rare diseases	<b>Process</b>	No Existing only one organisation Existing more than one organisations
	Having a directory of RD Patients' organisations	<b>Process</b>	No Yes In process
	Number of patients' associations	<b>Outcomes</b>	Number of patients associations
	Number of diseases covered by patients' associations	<b>Outcomes</b>	Number of diseases covered by patients' associations

# EUROPLAN INDICATORS FOR PATIENTS' EMPOWERMENT

ACTIONS	INDICATORS	TYPE	ANSWERS
Patients' organisations involvement in decisions affecting RD	Permanent and official patients' representatives in plan development, monitoring and assessment	Process	Yes, clearly established, substantially implemented and participation reimbursement considered Considered in the plan, not effectively implemented Not considered
	Participation of patients' organisations in the development of RD research strategies	Process	Yes Only as observers Are consulted before the final document is approved No
	Participation of patients organisations in the RD centres of expertise designation and evaluation	Process	Yes Only as observers Are consulted before the final document is approved No

# EUROPLAN INDICATORS FOR PATIENTS' EMPOWERMENT

ACTIONS	INDICATORS	TYPE	ANSWERS
<p>Support the activities performed by including patient organisations, such as:</p>	<p>Resource (funding) provided for supporting the activities performed by patient organisations</p>	<p>Outcomes</p>	<p>Number of Euros allocated for activities supporting patients' organisations</p>
<ul style="list-style-type: none"> <li>- Awareness raising</li> <li>- Capacity building and training</li> <li>- Exchange of information and best practices</li> <li>- Networking</li> <li>- Outreach to very isolated patients</li> </ul>	<p>Support to sustainable activities to empower patients, such as:</p> <ul style="list-style-type: none"> <li>- Awareness raising</li> <li>- Capacity building and training</li> <li>- Exchange of information and best practices</li> <li>- Networking</li> <li>- Outreach to very isolated patients</li> </ul>	<p>Outcomes</p>	<p>Number of activities per year sponsored within the plan</p>



# EUROPLAN INDICATORS FOR PATIENTS' EMPOWERMENT

ACTIONS	INDICATORS	TYPE	ANSWERS
<b>Building - supporting the existence of comprehensive help line for patients</b>	<b>Availability of Help line for RD</b>	<b>Process</b>	<b>Own help line Referred RD help lines Not formal decisions have been taken</b>

# EUROPLAN INDICATORS FOR SPECIALISED SERVICES

ACTIONS	INDICATORS	TYPE	ANSWERS
Compensating disabilities caused by rare diseases	Existence of official programs supporting patients and families with disabilities	Process	Not existing, not clearly stated Existing, clearly stated, partly implemented and enforced Existing, clearly stated and substantially implemented and enforced
	Existence of an official directory of social resources for patients with disabilities	Process	Yes No In preparation
Supporting rehabilitation programmes	Existence of programmes to support rehabilitation of RD patients	Process	Yes Yes, and it includes financial support No In preparation

# EUROPLAN INDICATORS FOR SPECIALISED SERVICES

ACTIONS	INDICATORS	TYPE	ANSWERS
<b>Supporting social services aimed at rare disease patients and their families</b>	Existence of national schemes promoting access of RD patients and their families to <b>Respite Care services</b>	<b>Process</b>	Yes Yes, and it includes financial support to patients / families No In preparation
	Existence of public schemes supporting <b>Therapeutic Recreational Programmes</b>	<b>Process</b>	Yes Yes, and it includes financial support to patients / families No In preparation
	Existence of programmes to support <b>integration of RD patients in their daily life</b>	<b>Process</b>	Yes Yes, and it includes financial support to patients / families No In preparation



# **WORKSHOP PATIENT EMPOWERMENT AND SPECIALISED SERVICES**

## **FURTHER GUIDELINES FOR DISCUSSION**

# INVOLVEMENT OF PATIENTS AND THEIR REPRESENTATIVES IN DECISION MAKING-PROCESSES

How to involve and empower patients, particularly:

- In the elaboration of national plans
- In the provision of information
- In the establishment and management of Centres of Expertise / European Reference Networks
- In the definition of the RD research policy
- Other areas such as the establishment and management of registries, clinical trials, evaluation of clinical added value of drugs, therapeutic education programmes, medical, paramedical and social workers training...
- How to ensure, through appropriate funding mechanisms, patient representativeness in decision-making processes relevant to RDs?

# SUPPORT TO THE ACTIVITIES PERFORMED BY POs

- How to support activities performed by patient organisations, such as:
  - awareness-raising,
  - capacity-building and training,
  - exchange of information and best practices,
  - networking,
  - outreach to very isolated patients.
- What mechanisms can be put in place to support patients' empowerment activities and their representativeness in EU-wide instances?

# SPECIALISED SOCIAL SERVICES

## Respite Care Services

## Therapeutic Recreational Programmes

### Services aimed at the integration of patients in daily life

- What kind of programmes exist in your country to support patients and families with RD and/or disabilities in general?
- What kind of schemes or programmes do exist supporting access of RD patients to Respite Care Services, Therapeutic Recreational Programmes and services aimed at the integration of patients in daily life ?
- What can be done to improve their availability and accessibility of such services, including public funding?
- How are specialised social services financed? By government institutions and budget? By private initiative or patient associations?

# HELP LINES

- What kind of help lines (all diseases) exist in your country to assist RD patients and healthcare professionals?
- How to develop or consolidate existing patient-run help line services for RD?
- How to improve the service offered? How to improve their visibility esp. for patients?
- National measures to establish the 116 European number
- How are help lines financed? By private initiative or patient associations? Is there any government funding?
- How to ensure their long-term sustainability?



# **WORKSHOP PATIENT EMPOWERMENT AND SPECIALISED SERVICES**

## **PROPOSALS FROM THE AUDIENCE**