

Hrvatski savez za rijetke bolesti

SOCIAL POLICY THE ROLE OF PATIENT ORGANISATIONS: CASE STUDY OF CROATIAN ALLIANCE FOR RARE DISEASES Vlasta Zmazek

Madrid, EMM 2015.

- 20 patient organisations
 Over 500 individual patient members
 More than 400 diagnosis
- Raising public awareness
- Help line
- Orpahnet Croatia

PROBLEMS / SOLUTIONS

- Debra Croatia
- Firefly association for helping children and families facing malignant diseases
- Croatian PKU Association
- Croatian Hemophilia Society



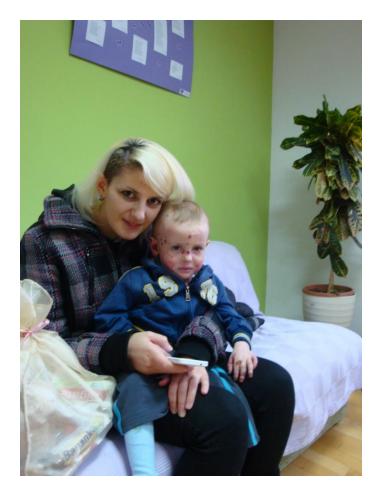
- Gathering & education
- Information on social rights
- Advocacy
- Rehabilitation
- Summer camps
- Cooking classes
- Creative workshops
- 24 hour service

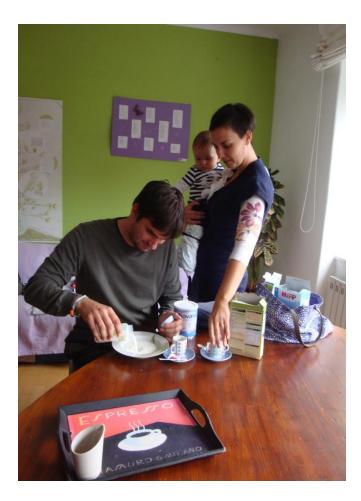
DEBRA CROATIA



- Gathering and education team of specialists
- Regular contacts with EB patients & families
- Accommodation for EB patients & families
- Updating with news in treatments and research
- Procuring and distribution in items for everyday care - link between distributers, insurance and GPs
- Link between patient and hospital / specialists (checkups and treatments)

PLACE FOR REST, SHARING EXPIRIANCE





ACCOMMODATION







ASSISTANCE







SUMMER CAMP











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Sport



Art exibition

FIREFLY - ASSOCIATION FOR HELPING CHILDREN AND FAMILIES FACING MALIGNANT DISEASES



CROATIAN PKU ASSOCIATION



CROATIAN HEMOPHILIA SOCIETY



ROLE OF:

- Inform
- Connect
- Share experience

patient organisation

BUT

- Kynesitherapy
- Rehabilitation
- Psycho-social therapy
- Education

social services

Croatian Alliance for Rare Diseases

<u>www.rijetke-bolesti.hr</u> <u>www.orpha.net/national/HR-HR</u>

