



**Hrvatski savez
za rijetke bolesti**

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

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- ◉ 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

ACTIVITIES

- ◉ 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 distributors, insurance and GPs
- ◉ Link between patient and hospital / specialists (checkups and treatments)

PLACE FOR REST, SHARING EXPIRIANCE



ACCOMMODATION



ASSISTANCE



SUMMER CAMP



LEISURE



WISH...





Sport



Art exhibition

FIREFLY - ASSOCIATION FOR HELPING CHILDREN AND FAMILIES FACING MALIGNANT DISEASES

The screenshot shows the homepage of the Krijesnica association website. The browser window title is "Naslovnica- KRIJESNICA" and the address bar shows "www.krijesnica.hr". The website has a green background with a yellow firefly logo in the top right corner. The main heading is "Dobrodošli na stranice Krijesnice!". Below this, there are several sections: "Novosti" (News) with a sub-heading "Zadnje novosti" and a featured article titled "Nutricionističko savjetovanje" dated 21.05.2015, accompanied by a large image of a face made of vegetables. To the left, there are sections for "Onkolog - i - JA" (Oncology - I - YOU) featuring a woman in a green dress, "FOTO GALERIJA" (Photo Gallery) with a slide titled "Kamp Fužine 2014", and "VIDEO GALERIJA" (Video Gallery) with a slide titled "Gosti na kampu _maorski plesaci". On the right side, there are sections for "DONATORI" (Donors) with the sub-heading "NAŠI DONATORI mala svjetla nade", "EDU ZONA" (Education Zone) featuring a book titled "edu&fun zona", and "SPONZORI" (Sponsors) listing "avalon", "B1 PLAKATI", and "dimedia". The Windows taskbar at the bottom shows the Start button, several open applications, and the system tray with the time 14:36.

CROATIAN PKU ASSOCIATION



CROATIAN HEMOPHILIA SOCIETY



ROLE OF:

- ◉ Inform
- ◉ Connect
- ◉ Share experience

} patient
organisation

BUT

- ◉ Kinesitherapy
- ◉ Rehabilitation
- ◉ Psycho-social therapy
- ◉ Education

} social services

Croatian Alliance for Rare Diseases

www.rijetke-bolesti.hr

www.orpha.net/national/HR-HR

