

DEBRA International Congress, Wellington, New Zealand

Resource Centre for EB

DEBRA Croatia

RareResourcenet

CQ Hotels November 24 2017.

Vlasta Zmazek,
DEBRA Croatia

DEBRA CROATIA



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DEBRA Croatia

Member of EBWB



- Founded 1996.
- Private visit by UK surgeon

Goal:

- Gather families with EB
- Disseminate information



First steps:

- London St' Thomas's Hospital
- Collaboration with Debra UK
- Coordinate Multi-disciplinary Team in Croatia



- Advocacy and media campaign
- Lobby for patient rights
- Needs / office space / professionalise organisation



Today ...ONE STOP SHOP

- 5 employees



- Office facilities - education / meetings
- Apartment for families- treatments and socialising



Activities:

- ▶ 24-hour information service
- ▶ public awareness, advocacy



- ▶ apartment



Bridge between patient and specialist

government funded dressings and treatments

education: families, specialists, students, school children



▸ psycho-social workshops and support



▸ rehabilitation weekends



Collaboration:

- Referral centre for EB/ University Hospital, Zagreb
- Faculty for social sciences
- Health sciences polytechnic
- Children's Hospital Zagreb
- Clinical Hospitals
- Educational rehabilitation univer
- Rare diseases Croatia

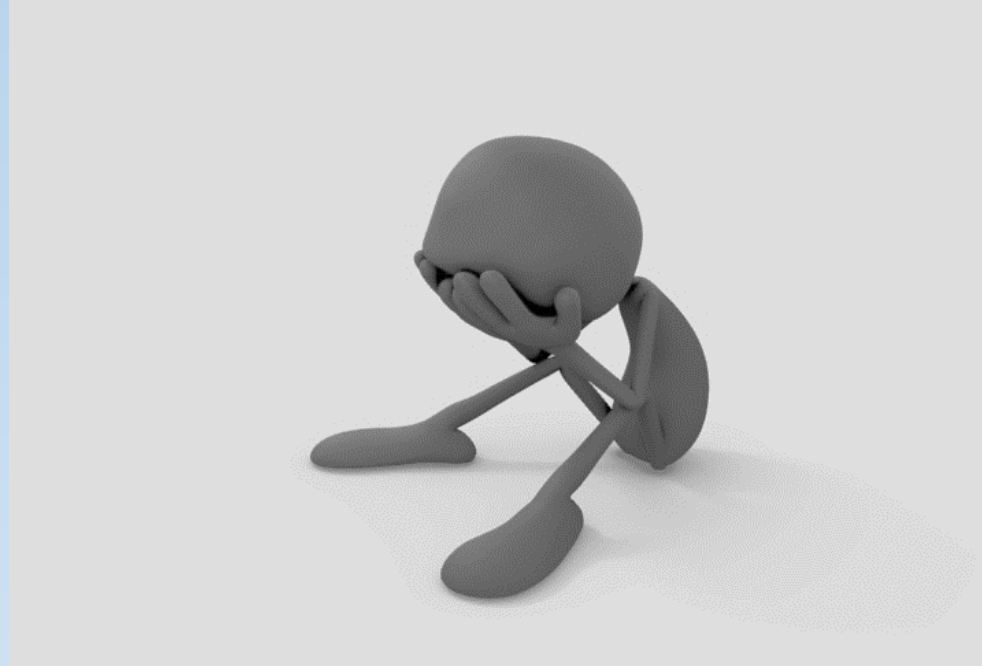
International:

- DEBRA International
- EURORDIS





financing...



Thank you!



