

**Sharing best practices on integrative approach  
to rare diseases in different countries**

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**Poland**

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*In collaboration with*

**EUROPLAN**

European Project for Rare Diseases National Plans Development



# Strategies for rare diseases

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- *Official definition of RDs used in your Country:  
5 (or less) patients per 10,000 citizens (definition adapted from EU)*
- *Please, provide information on national and/or regional measures, established by law, addressing specific aspects regarding RDs*

*Unfortunately, no specific official rules in this subject, apart from scientific studies (but they are not regular)*

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# Funding of actions, regarding rare diseases

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*How different issues, concerning RDs are funded:*

- *Prenatal screening – National Health Fund reimburses this, but only if clear medical indication occurs (e.g. the disease in siblings)*
- *Neonatal screening – Special programs for selected diseases*
- *Diagnostic genetic services – Several medical centers offer this*
- *Treatment (clinical management) – Special programs for selected diseases*
- *Orphan drugs + number of ODs available in the country – Selected orphan drugs are reimbursed. OD are available, but only a few of them are reimbursed.*
- *Rehabilitation – Available, but mostly not reimbursed*
- *Social care – Very poor (about 40 € per month)*

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# Provision of information for rare diseases

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- *Availability of website-based information – Some are available (e.g. [www.rzadkiechoroby.pl](http://www.rzadkiechoroby.pl), [www.gen.org.pl](http://www.gen.org.pl) and web pages of patient organizations)*
- *Help Lines – Very few*
- *Availability of an official list of RDs - No*

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# Research on rare diseases

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- *Availability of research programme for RDs – Yes, but based on individual grants of researchers*
- *Please, provide information on major sources – Ministry of Science and Higher Education*

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# Prevention

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- *Folic acid - No*
- *Prenatal screening – Yes, but only if there is a clear medical indication (otherwise it is possible, but not reimbursed)*
- *Neonatal screening – Yes, for selected diseases*
- *Delay of diagnosis – This is a serious problem for rare diseases*
- *Other preventive practices? - None*



# Empowerment of patients organisations

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- *Support to the activities of patient organisations – None*
- *Representation and consultation of patient organisations – Only recently patient organizations received invitation to participate in the Committee for Rare Diseases, established by the Ministry of Health*

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# Specialised social services

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- *Respite Care Services – Available but not reimbursed*
- *Therapeutic Recreational Programms – Only those organized by patient organizations*
- *Services aimed at the integration of patients in daily life – Currently some programs are available, mostly due to availability of funds form EU*