What is Patient Empowerment and How to Foster it?

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Patient Empowerment

Rare Diseases? Check them out on Flickr!
Patient Empowerment

Laura – aged 3
Patient Empowerment – a question of rights

Equal opportunities
Empowerment in Eurordis Mission

The European Organisation for Rare Diseases, EURORDIS, is a patient-driven alliance of patient organisations and individuals active in the field of rare diseases.

Eurordis’ mission is to build a strong pan-European community of patient organisations and people living with rare diseases, to be their voice at the European level, and - directly or indirectly - to fight against the impact of rare diseases on their lives.

To this end, Eurordis undertakes activities on behalf of its members, notably in favour of:

- Empowering rare disease patient groups
- Advocating rare diseases as a public health issue
- Raising public rare disease awareness, and also that of national and international institutions
- Improving access to information, treatment, care, and support for people living with rare diseases
- Encouraging good practices in relation to these
- Promoting scientific and clinical rare disease research
- Developing rare disease treatments and orphan drugs
- Improving quality of life through patient support, social, welfare and educational services
Understanding Empowerment

What do we mean by « empowerment »?

“the process of increasing capacity of individuals or groups to make choices and to transform those choices into desired actions and outcomes”

World Bank
What do we mean by « empowerment » of patients?

A “prerequisite for health” and “a proactive partnership and patient self-care strategy to improve health outcomes and quality of life among the chronically ill”

WHO
Features of Empowerment

« Empowerment » both relates to the individual as « self realisation » and identity formation

Creating a positive self image
A range of options
Own decision making power
Assertiveness
Ability to make change
Ability to discern and to listen
Empowerment: community based

But usually only happens in a group setting
Patient Empowerment

Breaking the silence to reduce discrimination or stigmatisation
Patient Empowerment

Getting informed and becoming an "expert" patient
Patient Empowerment

Gaining control e.g. through self management of treatment
Patient Empowerment

Having equal opportunities – is also about quality of life
Barriers for Patient Empowerment

What would the obstacles be?
Barriers for Patient Empowerment

Family life with rare diseases
Organising mutual support and self help activities
Patient Empowerment

Getting organized as a patient group
Patient Empowerment

Gaining support from society through awareness raising
Patient Empowerment

Learning how to organise surveys and data collection
Patient Empowerment

Communication
How to foster involvement in Research

Identify needs and priorities for basic, clinical, translational and social research
Sponsor research, understanding and promoting better designs of clinical protocols
Creating research networks
Foster participation in research projects at all appropriate levels, including Community level
Patient Empowerment

Understanding and promoting better designs of clinical protocols

The Charter
Empowerment through political involvement

Organising conferences and lobbying parliament committees to have national plans protocols and guidelines centres of expertise access to european reference centres registries and clear targets with measurable indicators

Benchmark with other MS!
Empowering the Patient Community

Obtaining representation on committees
Influencing policy making
Empowering the RD community

promoting involvement and consultation
Empowering the RD community

Striking the right balance
Keep the perspective
Patient Empowerment

Getting involved in advocacy
Taking Patient Empowerment to another level

Our involvement must take us beyond treatment and survival. We must highlight how society can help RD patients to be expressive and unleash their creative and innovative talents on the same line as other people.
The beauty of patient empowerment
Conclusion

« Rare Diseases, Europes challenge »