



Awareness & Health mutual funds in Belgium

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Euregio Meuse-Rhine Rare Disease Day
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1. Current situation and experience (1/3)

What do Belgian health mutual funds do for patients affected with rare diseases?

→ Health mutual funds in Belgium are not only health insurers, but also social entrepreneurs and movements, important actors of the civil society.

1.1. What do we do in terms of awareness at the individual/micro level?

- **Additional services of the Christian Mutuality (besides reimbursements):**
 - Social service:
 - Permanencies with individualised guidance (all mutualities in Belgium)
 - Chronic Diseases Info Point (PIMC)
 - Better information on rights and benefits
 - Dialogue with health fund and between patients

1. Current situation and experience (2/3)

- Movements that promotes a society where everyone is fully included
 - Altéo in Wallonia and Brussels
 - Samana in Flanders
- Other services
 - Autonomy counsellor
 - Support for informal caregivers
- **Informational services:**
 - Live via Mutualist Advisors and Social Service
 - Online via our website, chat, etc.
 - Newspapers of the Christian Mutuality and its movements
- **Annual actions to remind the patients' rights**

1. Current situation and experience (3/3)

1. 2. What do we do in terms of awareness at the **political/macro level**?

Health mutual funds are...

Co-managers of the Belgian health policy

→ Ability to report field problems to national level

Representatives of patients in different assemblies

→ Raising stakeholders and authorities' awareness

Data managers with study services

→ Raising public and politics awareness

Part of the Association Internationale de la Mutualité (AIM)

→ Cooperation at international level

→ Several hats that give us a place to influence policies and raise awareness on specific issues

2. Problems encountered (1/1)

Patients affected by rare diseases encounter problems linked to the lack of awareness on rare diseases...

2.1. Individual problems (micro level)

- Patients do not sufficiently know their rights and do not know that they can turn to our social service for help
- Nor the status « rare disease » nor the status « informal care takers » grant substantial advantages

But what is this lack of awareness linked to?

2.2. Problems at the macro level

- Rare diseases patients are not easily identifiable
- Few data on patients affected by rare diseases
- Difficult to grasp the unmet needs of the patients in order to bring them at the political level because rare disease patients are a heterogeneous population with very individual needs

3. Solutions and good practices (1/1)

What can be done to address this lack of awareness?

3.1. On the field

- More information and proactive approaches to patients with rare diseases
- More signals available to front-line workers to help them identify problematic situations more quickly

3.2. On political level

- Great opportunity given by the EMRaDi project and the field study (MC and Solidaris), which aims to model the RD patients' pathways in the EMR and thereby identify their (unmet) needs. **Very important that health mutual funds take part in such projects to improve their field services and their offer and to bring the needs of patients to the political level.**
- Cooperation between study services of the health mutual funds to produce statistics on rare diseases patients → Better public awareness
- Synergy with patient associations



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