

Summary Mid-Term Review of Strategic Plan of Hungarian Federation of Patients with Rare and Congenital Diseases (HUFERDIS), Hungary, 2016

The overall assessment of HUFERDIS's strategic plan is very positive, however together with HUFERDIS staff, the experts made some recommendations for future improvements.

I Goal: Access to health care - To fight for country wide access to special treatments, orphan drugs and medical devices and social care for rare disease patients.

HUFERDIS is playing an active role in implementing the Rare Diseases National Plan, however due to constant changes within the Ministry of Human Capacities, it became difficult to ensure a full and immediate implementation of governments' obligations. While HUFERDIS will continue to organize period meetings with the key healthcare stakeholders, it was concluded that HUFERDIS might provoke meaningful actions through international organizations and EU policy makers, so HUFERDIS slightly amended its strategic actions in order to reach international and European decision-makers in the future.

Thanks to secured funding aligned with the strategic objective, HUFERDIS is on track with the implementation of i) establishing accurate definition of disease (expanding the BNO codes; developing their general implementation, introduction, etc.), and keeping them up to date in parallel with the scientific developments, and ii) actively participating in the development and distribution of "Illness information protocols" (e.g. in universities, in the National Network Of District Nurses And General Practitioners) which contributes to the better communication between doctors and patients.

II Goal: Equal opportunities - To promote policies related to employment, education and mobility that enable patients with rare diseases to live in the society as equal citizens.

Due to other governments priorities and highly centralized educational system in Hungary, it was concluded that initially-set indicators for changing certain legislation acts proved to be unrealistic and had to be aligned to real circumstances. On the other hand, HUFERDIS succeeded in launching the first service: a telephone helpline and information centre Lifebelt Helpline. The launch of this centre improved the capacity of HUFERDIS to deliver effective, efficient and sustainable response to patients with rare disease

and congenital diseases and their families who are in need for information regarding health, educational and social services in the country.

III Goal: Awareness raising, advocacy - To raise awareness about and advocate for rare diseases amongst general public and specific stakeholders

The Review examined the performance of HUFERDIS strategic objective to raise awareness on rare disease and find out that HUFERDIS has succeeded in accomplishing multiple communication campaigns. For example, in 2015 HUFERDIS's outdoor poster was selected to the countrywide popular "Billboard poster of the year" exhibition, and in 2016 an unconventional rare disease related fashion show was organised which reached millions of Hungarians in the media. Unfortunately, these successes didn't result in concrete sponsorships or donations.

IV Goal: A strong Federation - To improve the effectiveness and sustainability of the organisation

Most of strategic actions under this goal are being implemented according to the plan. The Review find out that HUFERDIS needs to continue to strengthen its core organisational structure in order to ensure a sustainability and to be of a maximum support for the member patient organisations of rare diseases. This finding led to development of new strategic objectives. These include, inter alia: diversification of funding sources by building and systematically running a corporate giving program, building on volunteer capacities in the area of translation, logistics, organizing events, IT developments and administration as well as reactivating member organizations by providing valuable services aligned to regularly conducted needs assessments.