UNIVERSAL HEALTH IN ONE TOUCH

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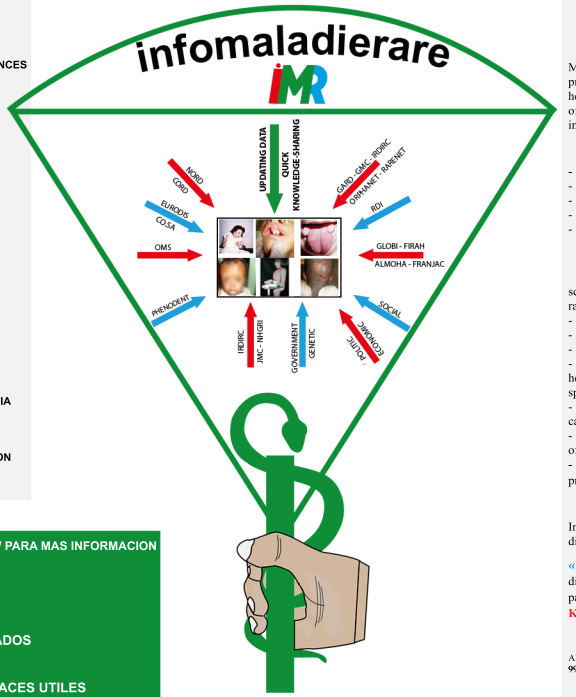
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ABSTRACT

UNIVERSAL HEALTH IN ONE TOUCH

Rare diseases affect one in 2000 people in all continents.[1] Patients suffer from often chronic disabilities.[2,3] Moreover, rare disease subject affected people(patients and their close relatives, researchers, doctors and health professionals) to situation in which ignorance check therapeutic research, diagnosis, guidance to specialists, heathcare providing and socioeconomic care of patients.[4] So, to answer the issues on the update and the transfer of adequate information and on early and daily effective patient care, we created an international and virtual information and knowledge sharing platform around rare diseases.

I- Objectives

- Map patients and specialists
- Inform and direct patients and international community
- Share knowledge on rare diseases for a better care
- Improve the living standards of the patients
- Increase patients life expectancy

II- Method

Main world information plateform on rare diseases, « informaladierare » shall be a technology, economic, scientific and sociopolitic innovation as regards communication, and data sharing on health and social issues about rare diseases. All contributors shall not depend on one another. They use the platform to :

- Mention all previous, actual and upcoming projects
- Inform the international community on occurrence of new phenotypes and diseases for better mapping
- Share world's politic, economic and social news about rare diseases
- Ease close collaboration between excellence centers using new strategies and developping projects usually helpful for other groups, organizations, patients, governments, academics or rare diseases and orphan product specialists.
- Make accessible to a large audience in one touch, information about speed diagnosis and rare diseases patients care on each continent according to environmental variability, disease evolution and patient phenotype
- Sensitize, educate, direct and motivate patients through an exchange and reliable data sharing forum regardless of geographic post, gender, race and cultural discrimination.
- Get patients involved and integrated into the carrying out of scientific, technical, economic and sociopolitical projects related to their pathologies.

III- Expected results

In this way, patients all around the world along with the international community involved in fighting against rare diseases shall always reliably advocate for a universal health using technology and media in « one touch ».

« infomaladierare » platform shall update international news about rare diseases, then promoting early rare diseases screening, mapping and follow-up ; increase of life expectancy and improvement of living standards of patients.

Keywords : rare diseases, patients, universal health, one touch, information, quick knowledge-sharing.

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