



The Holy See

**MESSAGE OF HIS HOLINESS POPE FRANCIS
TO PARTICIPANTS IN THE 31st INTERNATIONAL CONFERENCE ON RARE PATHOLOGIES
ORGANISED BY THE PONTIFICAL COUNCIL FOR HEALTH CARE WORKERS**

*To the Most Reverend Monsignor
Jean-Marie Mupendawatu
Secretary of the Pontifical Council for Health Care Workers*

I wish to send my cordial greetings to those taking part in the thirty-first international conference on the subject 'Towards a Culture of Health that is Welcoming and Supportive, at the Service of People with Rare and Neglected Pathologies', organised by the Pontifical Council for Health Care Workers, which I thank for this initiative. I also address grateful thoughts to the memory of my much lamented brother in the episcopate, H.E. Msgr. Zygmunt Zimowski, the former President of the Pontifical Council, who returned to the House of the Father last July.

Qualified experts, from every part of the world, have come together to explore the subject of 'rare' pathologies and 'neglected' diseases in their various aspects: from the medical-epidemiological to the socio-political and from the economic to the juridical-ethical. The conference intends to engage in a survey of the present situation, as well as an identification and a re-launching of practicable guidelines for action in this special medical/health-care scenario; having as founding values respect for the lives, the dignity and the rights of patients, together with a welcoming and supportive approach; and producing strategies for care and treatment that are moved by a sincere love for the actual person who suffers – from a 'rare' or 'neglected' disease as well.

The data that are available on these two chapters of medicine are emblematic. The most recent calculations of the World Health Organisation indicate that 400 million people in the world as a whole suffer from diseases defined as 'rare'. The scenario of 'neglected' diseases is even more dramatic because they affect over a billion people. They are for the most part infectious diseases and they are widespread amongst the poorest populations of the world, often in countries where access to health-care services is insufficient to cover essential needs, above all in Africa and Latin

America, in areas that have a tropical climate, with insecure drinking water and deficient hygienic/alimentary, housing and social conditions.

The challenge, from an epidemiological, scientific, clinical/care, hygienic and economic point of view is, therefore, enormous because it involves responsibilities and commitments on a global scale: international and national health-care and political authorities, health-care workers, the biomedical industry, associations of citizens/patients, and lay and religious volunteers.

This is an enormous challenge, but not an impossible one. Given the complexity of the subject, indeed, a multidisciplinary and joint approach is necessary; an effort that calls on all the human realities involved, whether institutional or otherwise. Amongst them there is also the Catholic Church which has always found a motivation and impulse in her Lord, Jesus Christ, who was crucified and rose again, the figure both of the patient (*'Christus patiens'*) and the physician (*'Christus medicus'*, the Good Samaritan).

At this point, I would like to offer some observations that can contribute to your reflections.

The first is that if the human person is the eminent value, it follows that each person, above all a person who suffers, because of a 'rare' or 'neglected' disease as well, without any hesitation deserves every kind of commitment in order to be welcomed, treated and, if possible, healed.

The effective addressing of entire chapters of illness, as is the case with 'rare' and 'neglected' diseases, requires not only qualified and diversified skills and abilities in health-care but also ones that are beyond health care – one may think of health-care managers, of administrative and political health-care authorities, and of health-care economists. An integrated approach, and careful assessments of contexts directed towards the planning and implementation of operational strategies, as well as the obtaining and management of the necessary sizeable resources, are required. At the base of every initiative, however, lies, first and foremost, free and courageous good will directed towards the solving of this major problem of global health: an authentic 'wisdom of the heart'. Together with scientific and technical study, the determination and wisdom of those who set themselves to work not only in the existential fringes of the world but also in its fringes at the level of care, as is of often the case with 'rare' and 'neglected' diseases, are, therefore, crucial.

Amongst the many who give of themselves generously, the Church, as well, has always been active in this field and will continue with this exacting and demanding pathway of nearness to, and the accompanying of, the person who suffers. It is no accident, therefore, that this thirty-first international conference wanted to adopt the following key words to communicate the sense – understood as meaning and direction – of the presence of the Church in this authentic work of mercy: *to inform*, in order to establish the state of present knowledge at a scientific and clinical/care level; *to care* for the life of patients in a better way in a welcoming and supportive approach; *to steward* the environment in which man lives.

The relationship between these diseases and the environment is decisive. Indeed, many diseases have genetic causes; in the case of others, environmental factors have a major importance. But even when the causes are genetic, a polluted environment acts as a multiplier of damage. And the greatest burden falls on the poorest populations. It is for this reason that I want once again to emphasise the absolute importance of respect for, and the stewardship of, the creation, our common home.

A second observation that I would like to bring to your attention is that it remains a priority of the Church to keep herself dynamically in a state of 'moving outwards', to bear witness at a concrete level to divine mercy, making herself a 'field hospital' for marginalised people who live in every existential, socio-economic, health-care, environmental and geographical fringe of the world.

The third and last observation relates to the subject of justice. Although it is true that care for a person with a 'rare' or 'neglected' disease is in large measure connected with the interpersonal relationship of the doctor and the patient, it is equally true that the approach, at a social level, to this health-care phenomenon requires a clear application of justice, in the sense of 'giving to each his or her due', that is to say equal access to effective care for equal health needs, independently of factors connected with socio-economic, geographical or cultural contexts. The reason for this rests on three fundamental principles of the social doctrine of the Church. The first is the principle of *sociality*, according to which the good of the person reverberates through the entire community. Therefore, care for health is not only a responsibility entrusted to the stewardship of the person himself or herself. It is also a social good, in the sense that the more individual health grows, the more 'collective health' will benefit from this, not least at the level, as well, of the resources that are freed up for other chapters of illness that require demanding research and treatment. The second principle is that of *subsidiarity* which, on the one hand, supports, promotes and develops socially the capacity of each person in attaining fulfilment and his or her legitimate and good aspirations, and, on the other, comes to the aid of a person where he or she is not able on his or her own to overcome possible obstacles, as is the case, for example, with an illness. And the third principle, with which a health-care strategy should be marked, and which must take the person as a value and the common good into account, is that of *solidarity*.

On these three cornerstones, which I believe can be shared by anybody who holds dear the eminent value of the human being, one can identify realistic, courageous, generous and supportive solutions to addressing even more effectively, and to solving, the health-care emergency of 'rare' and 'neglected' diseases.

In the name of this love for man, for every man, above all for suffering man, I express to all of you, participants in the thirty-first international conference of the Pontifical Council for Health Care Workers, the wish that you will have a renewed impetus and generous dedication towards sick people, as well as a tireless drive towards the greatest common good in the health-care field.

Let us ask the Most Holy Mary, Health of the sick, to make the deliberations of this conference of yours bear fruit. To her we entrust the commitment to making increasingly human that service which, every day, the various professional figures of the world of health perform for suffering people. I bless from my heart all of you, your families, and your communities, as I do those whom you meet in hospitals and nursing homes. I pray for you; and you, please, pray for me.

From the Vatican, 12 November 2016

Francis