

Drie aspecten bij de zorg voor mensen met een zeldzame ziekte

Address to participants of the International Conference on the Progress of Regenerative Medicine and its cultural impact



29 april 2016

Pope Francis

Dear Friends,

I am pleased to welcome all of you. I thank Cardinal Gianfranco Ravasi for his words and, above all, for having organized this meeting on the challenging problem of rare diseases within today's social and cultural context. During your discussions, you have offered your professionalism and high-level expertise in the area of researching new treatments. At the same time, you have not ignored ethical, anthropological, social and cultural questions, as well as the complex problem of access to care for those afflicted by rare conditions. These patients are often not given sufficient attention, because investing in them is not expected to produce substantial economic returns. In my ministry I frequently meet people affected by so called "rare" diseases. These illnesses affect millions of people throughout the world, and cause suffering and anxiety for all those who care for them, starting with family members.

Your meeting takes on greater significance in the Extraordinary Jubilee Year of Mercy; mercy is "the fundamental law that dwells in the heart of every person who looks sincerely into the eyes of his brothers and sisters on the path of life" (*Misericordiae Vultus*, 2). Your work is a sign of hope, as it brings together people and institutions from diverse cultures, societies and religions, all united in their deep concern for the sick.

I wish to reflect, albeit briefly, on three aspects of the commitment of the Pontifical Council for Culture and institutions working with it: the Vatican Science and Faith Foundation-STOQ, the Stem for Life Foundation, and many others who are cooperating in this cultural initiative.

The first is "increasing sensitivity". It is fundamentally important that we promote greater empathy in society, and not remain indifferent to our neighbour's cry for help, including when he or she is suffering from a rare disease. We know that we cannot always find fast cures to complex illnesses, but we can be prompt in caring for these persons, who often feel abandoned and ignored. We should be sensitive towards all, regardless of religious belief, social standing or culture.

The second aspect that guides your efforts is "research", seen in two inseparable actions: education and genuine scientific study. Today more than ever we see the urgent need for an education that not only develops students' intellectual abilities, but also ensures integral human formation and a professionalism of the highest degree. From this pedagogical perspective, it is necessary in medical and life sciences to offer interdisciplinary courses which provide ample room for a human formation supported by ethical criteria. Research, whether in academia or industry, requires unwavering attention to moral issues if it is to be an instrument which safeguards human life and the dignity of the person. Formation and research, therefore, aspire to serve higher values, such as solidarity, generosity, magnanimity, sharing of knowledge, respect for human life, and fraternal

and selfless love.

The third aspect I wish to mention is “ensuring access to care”. In my Apostolic Exhortation *Evangelii Gaudium* I highlighted the value of human progress today, citing “areas such as health care, education and communications” (52). I also strongly emphasized, however, the need to oppose “an economy of exclusion and inequality” (53) that victimizes people when the mechanism of profit prevails over the value of human life. This is why the globalization of indifference must be countered by the globalization of empathy. We are called to make known throughout the world the issue of rare diseases, to invest in appropriate education, to increase funds for research, and to promote necessary legislation as well as an economic paradigm shift. In this way, the centrality of the human person will be rediscovered. Thanks to coordinated efforts at various levels and in different sectors, it is becoming possible not only to find solutions to the sufferings which afflict our sick brothers and sisters, but also to secure access to care for them.

I encourage you to nurture these values which are already a part of your academic and cultural programme, begun some years ago. So too I urge you to continue to integrate more people and institutions throughout the world into your work. During this Jubilee Year, may you be capable and generous co-operators with the Father’s mercy. I accompany you and bless you on this journey; and I ask you, please, pray for me. Thank you.