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Message of the Prefect of the Dicastery for Promoting Integral Human Development for the 11th Rare Disease Day (28 February)

The following is the Message of the Prefect of the Dicastery for Promoting Integral Human Development, His Eminence Cardinal Peter Kodwo Appiah Turkson, for the 11th Rare Disease Day on the theme “ShowYour Rare. Show You Care” (#ShowYourRare) held today, 28 February.

Message of Cardinal Peter Kodwo Appiah Turkson

To the Presidents of the Episcopal Conferences,
to the Bishops responsible for Health Pastoral Care,
to Men and Women Religious,
to socio-health and pastoral workers,
to Volunteers and to all persons of good will,
and, above all, to the dear Brothers and Sisters suffering from rare diseases, and to their family members.

This eleventh edition of the Rare Disease Day, entitled: “Show Your Rare. Show You Care”, is intended to place emphasis on medical-scientific research on the subject. Despite the considerable progress made so far, little is known of many of the thousands of identified rare diseases and there is still limited care for the people, numbering about 400 million, who are carriers. Indeed, for a thousand of these diseases, even a basic scientific knowledge does not exist. Research proceeds slowly and this remains one of the main aspects to consider in the context of action aimed at the effective cure of rare diseases.[1]

It is known that rare diseases are neglected by the large investments of drug multinationals, which almost exclusively finance research on the most common diseases. For this reason, with reference to genetic diseases we speak of “orphan” diseases, and often only the sick themselves give voice to it, organizing themselves in specialized associations. But while diseases and drugs may be “orphans”, we can not leave people as orphans. Every patient must be welcomed and loved and no illness must condemn him to abandonment and marginalization. Jesus Himself taught us that “the human person is always precious, always endowed with a dignity that nothing and no one can erase, not even disease”.[2]
Standing alongside those suffering from rare diseases, I urge the public authorities to make a decisive

contribution to research, involving all available agencies and companies, networking the best knowledge, funding and medical practices. In order for research projects to be truly effective, they need to be adopted and implemented by the international community. Cooperation between the World Health Organization, states and large non-governmental organizations is the main road to making the fight against rare diseases more effective. The creation of an international research network will facilitate the achievement of a greater number of diagnoses, and early diagnoses, reducing the number of people worldwide who have to live with a rare, undiagnosed disease.[3]

I thank all patient associations, clinicians, scholars, health professionals, pharmaceutical companies, pharmacies, hospitals and institutions who promote and support scientific research. My thanks also go to all people of good will who collaborate in this beneficial enterprise. In particular, I address an appeal to the pharmaceutical industry to voluntarily donate part of its profits to research into rare diseases. This is a truly urgent cause that cannot be postponed.

With regard to research areas, it now seems essential that environmental medicine should be part of it; indeed, it assesses the correlation of rare diseases with increasingly incisive environmental agents, particularly in so-called industrialized civilizations. In this regard, Pope Francis warns: “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”.[4]

The Church, through her numerous health institutions, which include excellent research centres, closely follows the situation and conditions of people suffering from rare diseases in every part of the world. The Holy Father Francis strongly desired that attention to these people become a priority in the work of the new Department for Promoting Integral Human Development. Therefore today's Eleventh Rare Disease Day is a valuable occasion for reaffirming the commitment of this new Dicastery of the Roman Curia and, with it, of the whole Church, in favour of people suffering from rare diseases, and their families. “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”.[5]
To Mary, loving Mother of the Church, I entrust all those who are affected by rare diseases, their families, healthcare workers, and all those who every day stand courageously by their side.

Cardinal Peter K.A. Turkson
Prefect

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[1] Cf. Cardinal Pietro Parolin, opening speech at the 31st International Conference: “*Towards a culture of health that is welcoming and supportive at the service of people with rare and neglected pathologies*”, promoted by the Pontifical Council for Health Pastoral Care, Vatican City, 10-12 November 2016: “Dolentium hominum”, 91, p.9.

[2] Pope Francis, address at the Audience with Huntington’s disease patients and their families, Vatican City, 18 May 2017.

[3] Cf. M Aramini, *Curare tutti per realizzare una vera fraternità:* Conclusions and recommendations of the 31st International Conference *“Towards a culture of health*…”: “Dolentium hominum”, 91, pp. 90, 95.

[4] Pope Francis, Message to the Participants in the 31st International Conference: “*Towards a culture of*

health…”, 12 November 2016.

[5] *Ibid.*