



# SALA STAMPA DELLA SANTA SEDE **BOLLETTINO**

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## **Rare and neglected pathologies: theme of the International Conference of the Pontifical Council for Healthcare Workers**

“Towards a culture of health that is welcoming and supportive at the service of people with rare and neglected pathologies” is the theme of the 31st International Conference of the Pontifical Council for Healthcare Workers (Health Pastoral Care), which will take place in the Vatican’s New Synod Hall from 10 to 12 November and was presented this morning in the Holy See Press Office.

The speakers were Msgr. Jean-Marie Mupendawatu and Fr. Augusto Chendi, M.I., respectively secretary and under-secretary of the Pontifical Council for Healthcare Workers (Health Pastoral Care); Dr. Marco Tartaglia, head of the research department on rare diseases and genetic disorders at the Bambino Gesù Paediatric Hospital, Rome; and Dr. Claudio Giustozzi, national secretary of the Italian cultural association “Giuseppe Dossetti: I Valori-Sviluppo e Tutela dei Diritti” ONLUS.

The explained that according to the World Health Organisation (WHO, 2016), a disease is considered rare when it affects one person in two thousand, or fewer. From around five to eight thousand pathologies are defined in this way, of which 80 per cent are of genetic origin, and often life-threatening. It is estimated that around 400 million people worldwide are affected.

The WHO also estimates that more than a billion people, of whom almost half are children, are affected by “neglected” illnesses. The majority have an infectious cause and are widespread in geographical areas with a tropical climate, where the populations live without access to drinking water, with poor hygiene, inadequate housing conditions and limited or no access to healthcare services; in summary, in conditions of poverty that cause grave health problems for the world’s poor”. This situation poses a great challenge not only from an epidemiological, scientific and clinical point of view, but also from a cultural and political perspective, clearly indicating the need for responsibility and commitment at global level by all interested parties.

“The Church, which throughout her two millennia-long attention for the world of the sick has always been aware of service to the suffering and the ill as an integral part of her mission, intends by organising this conference to place herself at the service of those affected by rare and neglected pathologies, offering a response of an educational, cultural and pastoral nature. The treatment and care of the sick in general and those affected by

rare and neglected pathologies in particular are an inescapable work of evangelical corporal mercy. This pastoral urgency, with special attention to healthcare workers and decision-makers, finds in Pope Francis' ecclesial vision a renewed zeal, as demonstrated by the various initiatives and actions promoted and realised in this current Extraordinary Jubilee of Mercy".

The Conference, to be attended by 320 people from more than fifty countries, is structured according to three key themes, which constitute the pedagogical key to its work: reform, to focus on current knowledge both in a scientific and a clinical sense; to treat better and with a welcoming and fraternal approach to the life of the patient; and to protect the environment in which humankind lives.

Msgr. Mupendawatu concluded by repeating the Holy Father's words, which appear in the Presentation of the Conference Programme: "The Pope considers it to be a priority for the Church, in this historic moment, to be dynamically 'outbound' to offer concrete witness to Divine Mercy, making herself a 'field hospital' for the 'rejected' who live in every existential, socio-economic, healthcare, environmental and geographic periphery in the world".

The initiatives that form part of the Conference programme will include a meeting of European Catholic Healthcare Institutions, and a photographic exhibition on rare and neglected illnesses that can be visited in the entrance of the Paul VI Hall, from Thursday 10 November.

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