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Audience of the Holy Father with a delegation from UNIAMO – Italian Federation for Rare Diseases

This morning, in the Vatican Apostolic Palace, the Holy Father Francis received in audience a delegation from the Italian Federation for Rare Diseases (UNIAMO).

During the audience, the Pope spoke with the children present and handed his prepared address to the president of the Federation.

The following is the address the Holy Father had prepared for the occasion, and the words spoken during the meeting:

Address of the Holy Father

Dear brothers and sisters, good morning and welcome!

I thank the President for her kind words, and I greet you all, who form part of the Italian Federation for Rare Diseases. I have had the opportunity to greet you other times after the Angelus, on the occasion of the World Day for Rare Diseases, which is held on 28 February. Instead, today we can get to know each other better and share your hopes and your sufferings. *To share*, as your motto says, which is summarized in the word "*Uniamo*", let us unite. Let us unite our experiences, let us unite our strengths, let us unite our hopes. This key word of yours is fundamental and merits reflection.

The first value of your organization is that of sharing. At the beginning it is a necessity, then it becomes a choice. When a father and a mother discover that their child has a rare disease, they need to meet other parents who have lived and are living the same experience. It is a need. And since the disease is rare, it becomes essential

to refer to an association that brings together people who deal with that disease every day: they know the symptoms, the therapies, the treatment centres and so on. At the beginning this is an obligatory route: a way out of the anguish of finding oneself alone and unarmed in front of an enemy. Gradually, though, the way of sharing becomes a choice, sustained by two motivations. The first is realizing that it is necessary, it helps, it offers solutions, at least temporarily, it enables us to orient ourselves a little in the fog of the situation. And the second motivation comes from the pleasure of human relationships, from the good of friendship with people who until yesterday we did not even know, and who now confide their experiences to us to help us bear a very burdensome situation together. This is the first great value that I see in you, in your association.

There is then another value, equally important but different, both on a social and also political level. It is the potential that an association such as yours has to make a decisive contribution to the common good. In this case, to improve the quality of the health service of a country, a region, an area. Indeed, good politics depends also on the contribution of associations, which, in specific matters, have the necessary knowledge and attention towards people who risk being neglected. Here is the decisive point: it is not a matter of claiming favours for one's own category, this is not good politics; but rather it is a question of fighting so that no one is excluded from the health service, no one is discriminated against, no one is penalized. And this, starting from an experience like yours that is strongly at risk of marginalization. Let me give you an example: entities like yours can apply pressure to overcome national and commercial barriers to the sharing of results of scientific research, so that we can achieve objectives that today seem very distant.

Certainly, it is difficult to commit on behalf of everyone when you are already struggling to face your own problem. But precisely here lies the strength of the association, and even more so the federation: the capacity to give a voice to the many who, alone, would not be able to make themselves heard, and thus represent a need. In this regard, it would be important to involve and listen to patient representatives from the very first phases of decision-making processes. Indeed, associations not only ask, but also give. In your relations with institutions at various levels, you not only ask, but also give: knowledge, contacts, and above all people, people who can lend a hand for the common good, if they work with a spirit of service and civic sense.

Dear friends, thank you for this very welcome visit. I encourage you to go forward in your commitment. I ask Our Lady to accompany every person and every family who faces a rare disease. I wholeheartedly bless you and all your community. And I ask you, please, to pray for me. Thank you!

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Words of the Holy Father

During the audience, the Holy Father gathered some children around him, handing them rosary chaplets, and addressed the following words to them:

At times, we prepare things to say, all the ideas… But reality speaks better than ideas. The real speech was made by them today, gathering round spontaneously, giving the best of themselves, a smile, a curiosity, reaching out their hand to take the rosary – there are no fools here, none! They know how to do it well. And this was the sermon today, for us. Therefore, I thought that to continue to speak, after this living sermon, would not make sense. I will give the text to the President, and in this way she can make it known to you. And after the blessing, I will greet you all. This is the text I wanted to say. But the true sermon was what they did, with their limitations, their illnesses, but they made us understand that there is always the possibility to grow and to go forward.

And to you, thank you, thank you for this. This is the prize for you: seeing how these children have done. Thank you.