



The Holy See

ADDRESS OF HIS HOLINESS POPE FRANCIS TO HUNTINGTON'S DISEASE PATIENTS AND THEIR FAMILIES

*Paul VI Audience Hall
Thursday, 18 May 2017*

[Multimedia]

Dear Brothers and Sisters,

I welcome you with joy, and I greet each one of you present at this opportunity for meeting and reflection dedicated to Huntington's Disease. I wholeheartedly thank all those who worked to make this day possible. I am grateful to Dr Cattaneo and to Mr Sabine for their introductory words. I would like to extend my greeting to all people who, in their body and in their life, carry signs of this disease, as well as those who suffer from other so-called rare diseases.

I know that some of you have had to brave a very long and difficult journey in order to be here today. I thank you and I am happy you are here. I have listened to your accounts and the difficulties you must face each day; I understand how much tenacity and dedication your families, doctors, health care workers and volunteers have as they support you in a journey that poses many uphill climbs, some of which are extremely difficult.

For far too long, the fears and difficulties that characterize the life of people affected by Huntington's Disease have surrounded them with misunderstandings and barriers, veritably excluding them. In many cases the sick and their families have experienced the tragedy of shame, isolation and abandonment. Today, however, we are here because we want to say to ourselves and all the world: "HIDDEN NO MORE!", "OCULTA NUNCA MAS!", "MAI PIU' NASCOSTA!". It is not simply a slogan, so much as a commitment that we all must foster. The strength and conviction with which we pronounce these words derive precisely from what Jesus himself taught us. Throughout his ministry, he met many sick people; he took on their suffering; he tore down the walls of stigma and of marginalization that prevented so many of them from feeling respected and

loved. For Jesus, disease is never an obstacle to encountering people, but rather, the contrary. He taught us that the human person is always precious, always endowed with a dignity that nothing and no one can erase, not even disease. Fragility is not an ill. And disease, which is an expression of fragility, cannot and must not make us forget that in the eyes of God our value is always priceless.

Disease can also be an opportunity for encounter, for sharing, for solidarity. The sick people who encountered Jesus were restored above all by this awareness. They felt they were listened to, respected, loved. May none of you ever feel you are alone; may none of you feel you are a burden; may no one feel the need to run away. You are precious in the eyes of God; you are precious in the eyes of the Church!

I now turn to the families. Those who experience Huntington's Disease know that no one can really overcome loneliness and despair if they do not have people at their side who, with self-sacrifice and steadfastness, make themselves 'travel companions'. You are all this: fathers, mothers, husbands, wives, children, brothers and sisters who, on a daily basis, silently but effectively, accompany your family members on this difficult path. For you, too, at times, the path is an uphill climb. For this reason, I encourage you, too, not to feel you are alone; not to give in to the temptation of the sense of shame or guilt. The family is the privileged place of life and of dignity, and you can cooperate to build that network of solidarity and of help that the family alone can guarantee, and which the family is first called to live.

I speak to you, physicians, health care workers, volunteers of the associations that are involved with Huntington's Disease and with those who suffer from it. Among you there are also workers from the *Ospedale Casa Sollievo della Sofferenza*, who, both with assistance and with research, express the contribution of a work of the Holy See in this most important field. The service that you all provide is valuable, because it is surely your dedication and your initiative that give tangible shape to the hope and motivation of the families who trust in you. The disease poses many challenges related to diagnostics, therapy and assistance. May the Lord bless your work: may you be a point of reference for patients and their families who, in various circumstances, find themselves having to face the already difficult trials that the disease entails, in a social-health care context which often is not oriented to the dignity of the human person. In this way, however, difficulties multiply. Often adding to the disease are poverty, forced separations and a general sense of dismay and mistrust. For this reason, national and international associations and institutions are vital. You are like hands that God uses to sow hope. You are the voices that these people have so as to claim their rights!

Lastly, geneticists and scientists are present here, who, for some time, sparing no energy, have dedicated themselves to studying and researching a treatment for Huntington's Disease. Clearly, there is a great deal of expectation surrounding your work: resting on your efforts are the hopes of finding the way to a definitive cure for the disease, but also of improving the living conditions of

these brothers and sisters, and of accompaniment, especially in the delicate phases of diagnosis, at the onset of the first symptoms.

May the Lord bless your task! I encourage you to always pursue it with means that do not contribute to fuelling that “throw-away culture” that at times infiltrates even the world of scientific research. Some branches of research, in fact, utilize human embryos, inevitably causing their destruction. But we know that no ends, even noble in themselves, such as a predicted utility for science, for other human beings or for society, can justify the destruction of human embryos.

Brothers and sisters, as you see, you are a large and motivated community. May the life of each of you — both of those who are directly affected by Huntington’s Disease and those who work hard every day to support the sick in their pain and difficulty — be a living witness to the hope that Christ has given us. Even through suffering there passes a path of abundant good, which we can travel together.

I thank all of you! May the Lord bless you, and please, do not forget to pray for me, as I will pray for you. Thank you.