

Message from Mrs Clio Napolitano, wife of the President of the Italian Republic, on the occasion of the First European Rare Disease Day (29 February 2008)

On the occasion of the “First European Rare Disease Day”, I should like to express to all members of the *Federazione Italiana Malattie Rare* – UNIAMO, to members of the European Organisation for Rare Diseases – EURORDIS, and to members of all the associations dealing with rare diseases, my deepest appreciation on behalf of the victims of rare diseases and their families.

Helping to raise awareness of rare diseases, as you are doing, can help to hasten diagnoses and to come up with effective therapies. When informing people about competent health centres and suitable therapies, your activities play an important role in helping people affected by rare disorders and their families to receive assistance on a timely basis, especially when organized information and support networks are still lacking. Your promotion of contacts and relations between patients and families facing the same problems is also important: diseases, and rare diseases in particular, often trap their victims inside bubbles of social isolation, which have to be burst in order to avoid one problem piling on top of another.

Your awareness-raising activities, and the pressures you apply on the public health sector and the pharmaceutical industry are decisive in securing investments for research on new drugs, offering fresh hope for patients. It is significant that you propose to place the following purpose on the public agenda: “Rare diseases: a public health priority”. It is also important that you accompany your pressure on the public health sector with efforts aimed at raising funds from foundations and the private sector.

Only a few people reflect on the fact that rare diseases affect millions of people in Italy, Europe and the world. Your activities are therefore of enormous social significance and I think you may rightly be satisfied with the European Commission’s initiative in drafting a Communication on Rare Diseases last December.

I am confident in the complete success of this First European Rare Disease Day, “A rare day for very special people”, which will be celebrated on February 29th this year, and I warmly hope that you will benefit from all the attention and support which you deserve so much.