

Statement by President Tarja Halonen,

Former President of Finland,

Co-Chair of the WHO-OHCHR High Level Working Group for
the Health and Human Rights of Women, Children and Adolescents

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Ladies and Gentlemen,

Dear Participants to the Inauguration of
the NGO Committee for Rare Diseases,

While other prior commitments prevented me from being with you today in New York City, I still wish to thank you for inviting me, and to assure you of my enthusiastic support to this new and important initiative.

As you well know, the advancement of human and social rights for vulnerable populations, and women in particular, has been a standing priority of my political action all through the years – not just during my Presidency of the Republic of Finland but actually as early as the late 1960's when I served as the Social Affairs Secretary of the National Union of Finnish Students and later in the national Parliament's Social Affairs Committee, first as a backbencher as of 1979 and later as its chairwoman from 1985 to 1986. I also served as a Minister at the Ministry of Social Affairs and Health subsequently.

Today like yesterday, I firmly believe that there shall be no genuine progress in addressing the grand challenges of human rights and social development if we do not recognize how essential the need is to tirelessly promote the rights and equal opportunities of vulnerable populations – women and children first and foremost.

In June 2005, I had the honour to deliver a keynote address to the UN Economic and Social Council, just next door to where you are today, in which I commented that "poverty so often wears the face of a woman". The same, alas, could very much be said of ill health. And this is why I feel an immense sense of responsibility and duty for serving, since September this year, as Co-Chair of the new High-Level Working Group for the Health and Human Rights of Women, Children and Adolescents jointly set up by the World Health Organization and the Office of the UN High Commissioner for Human Rights.





The Global Gathering for Rare Diseases

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As I approach this new mission, I find that rare diseases offer an interesting case-in-point. Many of them are of genetic origin, and tend to manifest from early childhood onwards with dramatic consequences – nearly 30% of persons living with a rare disease diagnosed in early childhood die before age 5. Affected individuals are left in dire need, not only of effective therapies (which are so severely lacking today) but for the most part of stronger support to access care, education, and the enjoyment of their most essential socio-economic rights. In other words, to be included as equal citizens and enabled to express their full potential in society.

Women also tend to be impacted disproportionately, be it as patients themselves but also – as happens still too frequently – as lifelong carers of persons suffering from a rare disease, often to the very detriment of their own health, inclusion and social pursuits. It is unacceptable that a rare disease should in our times continue to represent a sentence without appeal to poverty, stigmatization and exclusion.

In that respect, the initiative to establish the new NGO Committee for Rare Diseases must be saluted. The Committee shall give more visibility to issues that require urgent, decisive action and global thinking. And it will also provide a much needed platform for civil society organizations worldwide to engage and fruitfully collaborate with UN agencies, national governments, academic and medical experts and the private sector in the search for new solutions.

I wish you all an excellent meeting, and look forward to following the future activities of the Committee.

President Tarja Halonen