

Aging is something we can be sure happens to us all regardless of gender, ethnicity, socio-economic or disability. For certain groups in our society aging comes with a great deal of uncertainty or fear, as a consequence of social support diminishing or being completely forgotten. People with rare diseases are not only exposed to the exclusion and discrimination that can come with old age, they also suffer a risk of being further set aside by society due to their diagnosis.

The NGO Committee for Rare Diseases (CfRD) aims to increase visibility, extend and share knowledge, connect and promote international, multi-stakeholder collaboration and actions for rare diseases. Additionally, the CfRD has the ambition to align rare diseases as a global priority in public health, research and medical and social care policies. These efforts concern the entire lifetime of an individual; from childhood and adolescence, to adulthood and ultimately old age. People living with rare, complex and disabling diseases, suffer serious unmet health and social needs that effect their well-being, autonomy and fundamental human rights.

### What is a rare Disease?

There are over 6,000 identified rare diseases. Even though one disease may be rare, the number of people affected by rare disease is huge. There is an estimated 30 million affected people in Europe alone, and an estimated 350 million affected individuals in worldwide.



The very notion of rarity means that rare disease communities, experts and industry professionals are often few in number and geographically scattered.

This means people living with a rare disease still remain vulnerable and marginalized, as often no one country, nor continent have the critical mass and knowledge alone to address the challenges of living with a rare disease.

### Aging and rare diseases

When considering “*Equality and non-discrimination*” and “*Neglect, violence and abuse*” with regards to people of old age, the perspective of rare diseases explicates one of the more exposed groups within this segment of the global population. The inclusion of a minority within the group would thus enable a deeper analysis of the issues affecting the group as a whole.

Issues regarding discrimination, such as health and social care, autonomy, and access to goods and services become even more acute for old people with rare diseases that put them even further outside of the norm with regards to functionality. If, and how, a nation addresses discrimination against this minority can therefore expose the level of its non-discriminating efforts with regards to its aging population. Similarly, addressing aspects of neglect and abuse from the perspective of older individuals with rare diseases and how exposed they are to such affronts would provide a broader understanding of the general disposition regarding limited functionality and the efforts made to address these from the society.

Therefore, CfRD wishes to take part in the eighth working session at the United Nations Headquarters in New York, taking place between the 5<sup>th</sup> and 7<sup>th</sup> of July 2017. This in order to lift the important topic of aging by including the aspect of older persons with rare diseases to the focus issues “*equality and non-discrimination*” and “*neglect, violence and abuse*”.