

Don't Stop Research on Rare Diseases!

Research on Rare Diseases (RD) and the care of patients living with them have specific needs. Due to the rarity of patients and the scarcity of information related to each rare disease, collaboration and maximum use of limited resources available is particularly necessary. Indeed, for most rare diseases no single institution, and in many cases no single country, has a sufficient number of patients to develop a sound knowledge on the disease and its care.

The EU Council Recommendation on Rare Diseases and the EU Parliament and Council Directive on Cross-Border Health Care witness the need and urgency for cooperation among Countries in collecting and sharing data to foster research and care regarding patients living with rare diseases. Indeed, these complex diseases are still largely unknown and are being approached, with promising but still occasional successes in the last few years, thanks to the new tools of biomedical and genetic research.

This positive perspective is now endangered in the Parliamentary discussion of the General Data Protection Regulation, which is opened by the [Draft Report](#), released by the rapporteur for the LIBE committee, Jan Philipp Albrecht (Germany), whose position is clarified by the disconcerting justification that “Processing of sensitive data for historical, statistical and scientific research purposes is not as urgent or compelling as public health or social protection. Consequently, there is no need to introduce an exception which would put them on the same level as the other listed justifications.”(Justification to Amendment 27).

Missing the opportunity of exploiting and sharing the small amount of data that are collected, will dramatically delay the improvement of health care of RD patients. **De facto, it would result in discrimination of RD patients regarding their right to quality health care** and will pose a serious ethical problem to the EU and national Institutions.

Therefore, I call the whole community interested in the advancement of health research, particularly on rare diseases, to [sign this petition](#) and [spread the word](#) on the need to sign it as soon as possible. The EU Parliament activities on the Regulation are already on going and the discussion is scheduled to be concluded by June 2013.

Please join us, here's the link to the petition site:

<http://www.change.org/en-GB/petitions/don-t-stop-research-on-rare-diseases-2>

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(The photograph, titled "The wait", has been selected from the works participating in the 5th Art Contest "[The Pegasus Flight](#)" (2013) aiming to promote social inclusion of patients living with rare diseases. It refers to the life of the only child in Europe, and one of the nine in the world, known to be affected by the X-linked Pigmentary Reticulate Disorder)