



EUROPEAN SOCIETY OF HUMAN GENETICS

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**European Society  
of Human Genetics**

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**From the President of the European Society for Human Genetics**

Attn.

Mrs Monica Ensini, Scientific Director EURORDIS  
Mr Walter Ricciardi, Mr Martin McKee, European Public Health Association (EUPHA)  
Mrs Ségolène Aymé, ORPHANET and Rare Disease Platform  
To whom it may concern

February 4th, 2013

Dear Sir, Dear Colleagues,

As President of the European Society for Human Genetics, I am sending this letter indicating our full support and endorsement to the EURODIS/OrphaNet/EUCERD statement regarding their opposition to the EU proposal on data security.

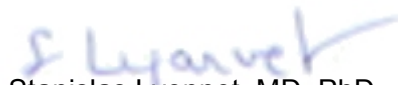
This initiative could ruin the many registry initiatives regarding genetic diseases. Indeed, many examples of research related to genetics and genetic diseases, including EU-supported researches, would have been impossible had such an amendment been passed. Among those: i) rare disease genetic registries, ii) genomic variant databases such as *Decipher*, iii) genetic syndrome diagnosis database and Forum such as *Dyscerne*.

These activities are among great advances in Human Genetics over the last 15 years. They are of a broad interest, have international recognition, and could be put a fundamental legal risk, should the amendment pass.


As an international scientific association, we strongly oppose such an amendment.


Together with the Executive Board of the ESHG, I very much hope that your action will be successful.

With all best wishes.

  
Stanislas Lyonnet, MD, PhD  
President

Jörg Schmidtke, MD, PhD  
Vice-president

  
Han Brunner, MD, PhD  
President-elect

  
Gunnar Houge, MD PhD  
Secretary General

European Society of Human Genetics