European rare disease patient federation condemns the use of genetic testing to establish racial origins

PRESS RELEASE - June 28, 2012. The European Organisation for Rare Diseases (EURORDIS) condemns the use of genetic testing to establish racial origins for political purposes and deems it unacceptable. The condemnation echoes the press release issued by the European Society of Human Genetics after a member of parliament from the Hungarian far-right Jobbik party used a genetic test to attempt to prove he did not have a Roma or Jewish ethnic background.

A genetic-diagnostic company called Nagy Gén scanned 18 positions in the MP's genome for variants that it said were characteristic of Roma and Jewish ethnic groups and concluded that Roma and Jewish ancestry could be ruled out.

Hungary's Medical Research Council (ETT), which advises the government on health policy, has asked public prosecutors to investigate Nagy Gén and concluded that the genetic test violates Hungarian law, which allows such testing only for health purposes.

"This sad case happening in Hungary today could happen in any other European country. Collectively, patients and families as well as all stakeholders, and more broadly all policy makers and indeed all citizens, we need to raise our level of vigilance so to prevent any potential genetic discrimination of all sorts and avoid misuse of scientific advancements intended to improve patients care" says Yann Le Cam, Chief Executive Officer of EURORDIS.

"This is appalling. EURORDIS, in consultation with HUFERDIS, the Hungarian Rare Disease Patient Alliance, strongly endorses ESHG's position" declares Terkel Andersen, President of EURORDIS.

"This is totally unacceptable exploitation of biological materials which represent useful information for patients," argues Flaminia Macchia, EU Public Affairs Director at EURORDIS.

Genetic testing is of particular importance to the rare disease community since it can be used to establish early diagnosis and prevention, timely treatment, as well as to give genetic counselling to the patient and the family at large and to raise awareness amongst couples in age to procreate.

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About EURORDIS

The European Organisation for Rare Diseases (EURORDIS) represents more than 500 rare disease organisations in 48 countries, covering more than 1,000 rare diseases. It is the voice of the estimated 30 million patients affected by rare diseases throughout Europe.

EURORDIS is a non-governmental patient-driven alliance of patient organisations and individuals active in the field of rare diseases, dedicated to improving the quality of life of all people living with rare diseases in Europe. It is supported by its members and by the French Muscular Dystrophy Association (AFM), the European Commission, and corporate foundations and the health industry. EURORDIS was founded in 1997. More information on: www.eurordis.org

About Rare Diseases

A disease is considered as rare when it affects less than one in 2000 people. Rare diseases are chronically debilitating or life-threatening. There is no cure today for the 6000 – 8000 rare diseases identified, of which 75% affect children. Due to their rarity, information is scarce and research is insufficient. People affected by rare diseases face common challenges such as diagnosis delay, misdiagnosis, psychological burden and lack of practical support for everyday life. About 30 million people suffer from a rare disease in Europe today.