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MOTION FOR A RESOLUTION

pursuant to Rule 133

on congenital central hypoventilation syndrome

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B8-0103/2017

Motion for a European Parliament resolution on congenital central hypoventilation syndrome

The European Parliament,

– having regard to Article 168 of the Treaty on the Functioning of the European Union,

– having regard to Rule 133 of its Rules of Procedure,

A. whereas congenital central hypoventilation syndrome (hereinafter 'CCHS') is a rare disease affecting 1 in 200 000 people, with autosomal dominant inheritance and involving a congenital lack of central respiratory control and diffuse impairment of the autonomic nervous system that may also affect digestive, cardiovascular and eye function, and which is caused by a mutation in the PHOX2B gene on chromosome 4p12;

B. whereas the overall mortality rate of CCHS is 38% with a median age at death of three months (Orphanet, 2006), but with patients living beyond that age developing autonomous daytime breathing in 85-90% of cases;

C. whereas diagnosis and rapid multidisciplinary care can prevent a child from dying during its first few months, but diagnosis is hindered by a lack of knowledge among medical practitioners regarding CCHS;

1. Encourages the Commission and Member States to support research into CCHS treatment and to raise medical practitioners' awareness of its diagnosis.