



Luxembourg, 2nd December 2009

**Call for expressions of interest as Commission appointees to the European Union
Committee of Experts on Rare Diseases – Patient's representatives**

This public call for expressions of interest relates to the appointment by the European Commission of members representing patients' organisations at the European Union Committee of Experts on Rare Diseases. Decision Commission C(2009)9181 final, of 30 November 2009, establishing a European Union Committee of Experts on Rare Diseases¹ lays down general rules concerning the criteria and procedure for the designation of the members of the Committee.

Article 3(1)(b) lays down that the Committee of Experts on Rare Diseases shall include "four members nominated by the Commission to represent patients' organisations". The members of the Committee shall be appointed for a term of three years, which could be renewable.

The Committee of Experts on Rare Diseases meets normally in Luxembourg or Brussels. Travel and subsistence costs for members of the Committee will be met by the European Commission. The main working language of the Committee is English.

Call for expressions of interest - how and by when?

Expressions of interest in being Commission appointees to represent patients' organisations should be notified to the European Commission. Each application must be completed in one of the official languages of the European Union, clearly indicating the applicant's nationality and including the necessary documentation. Expressions of interest should provide the following information:

I. Name, job title and qualifications of proposed member.

II. Representatives of which organisation(s).

III. Presentation of the organisation(s) represented, including the organisation's legitimacy (i.e. statutes registered in a Member State of the European Economic Area (EEA)), mission and objectives, focus on rare diseases, capability to represent patients, whether the governing body is elected, how accountability and transparency of funding and activities are ensured.

IV. Experience of the proposed member including that relevant to the tasks of the Committee of Experts on Rare Diseases.

V. Outline of any conflicts of interest that could affect impartiality.

¹ http://ec.europa.eu/health/ph_threats/non_com/keydo_rare_diseases_en.htm

VI. Motivation as to why the proposed member considers that he/she should be chosen as member of the Committee of Experts on Rare Diseases to represent patients' organisations in Europe.

VII. Curriculum Vitae of the proposed member.

Information should be sent by e-mail to arrive before **21st December 2009** to the following mailbox: laetitia.voneche@ec.europa.eu

Assessment criteria

Assessment of expressions will be based on:

- Whether the proposed member represents patients' organisations at a European level.
- Membership of the Committee of Experts on Rare Diseases will concentrate on associations with a pan-European coverage, rather than on national or regional organisations.
- In general preference is given to umbrella organisations covering several topics or mandated by other organisations to represent them in the Committee.
- Whether the proposed member has competencies and experience relevant to the tasks of the Committee of Experts on Rare Diseases listed in Article 2(3) of the Commission Decision.
- Ability and experience in representing organisations, and the characteristics of the organisation represented.

Appointment process

Based on the assessment criteria listed above, the European Commission will draw up a list of appointees.