

COMMISSION DECISION**of 27 July 2010****on the appointment of the members of the European Union Committee of Experts on Rare Diseases
set up by Decision 2009/872/EC**

(2010/C 204/02)

THE EUROPEAN COMMISSION,

Having regard to the Treaty on the Functioning of the European Union,

Having regard to Commission Decision 2009/872/EC of 30 November 2009 establishing a European Union Committee of Experts on Rare Diseases⁽¹⁾, and in particular Article 3(4) thereof,

Whereas:

- (1) According to Article 3(1) of Decision 2009/872/EC, the European Union Committee of Experts on Rare Diseases (hereinafter, 'the Committee') shall comprise 51 members and the corresponding alternates.
- (2) According to Article 3(4) of Decision 2009/872/EC, among these 51 members, the following members shall be appointed by the Commission: four representatives from patients' organisations, four representatives of the pharmaceutical industry, nine representatives of ongoing and/or past Community projects in the field of rare diseases financed by programmes of Community action in the field of health⁽²⁾ including three members of the pilot European Reference Networks on rare diseases, and six representatives of ongoing and/or past rare diseases projects financed by the Community Framework Programmes for Research and Technological Development⁽³⁾. The 27 representatives of the Member

States shall be appointed by the Member States. The representative of the European Centre for Disease Prevention and Control (ECDC) shall be appointed by the ECDC.

- (3) In accordance with Article 3(4) of Decision 2009/872/EC and with a view to selecting these members the Commission published four calls for expression of interest which specified the required qualifications and conditions to become member of the Committee. These calls led to lists of suitable candidates from which, based on the assessment criteria listed in the calls, the Commission hereby appoints the said members,

HAS DECIDED AS FOLLOWS:

Sole Article

The experts listed in the Annex to this Decision are appointed as members of the EU Committee on Rare Diseases.

Done at Brussels, 27 July 2010.

For the Commission
John DALLI
Member of the Commission

⁽¹⁾ OJ L 315, 2.12.2009, p. 18.

⁽²⁾ OJ L 155, 22.6.1999, p. 1; OJ L 271, 9.10.2002, p. 1; OJ L 301, 20.11.2007, p. 3.

⁽³⁾ OJ L 412, 30.12.2006, p. 1.

ANNEX

List of experts appointed by the Commission as members of the EU Committee on Rare Diseases**1. Patients' organisations***1.1. List in alphabetical order of representatives from patients' organisations*

Last name	First name	Institute or organisation of affiliation
Dan	Dorica	European Organisation for Rare Diseases
Grønnebak	Torben	European Organisation for Rare Diseases
Le Cam	Yann	European Organisation for Rare Diseases
Nourissier	Christel	European Organisation for Rare Diseases

1.2. List in alphabetical order of alternates from patients' organisations

Last name	First name	Institute or organisation of affiliation
Geissler	Jan	European Organisation for Rare Diseases
Kent	Alastair	European Organisation for Rare Diseases
Pizzera-Piantanida	Bianca	European Organisation for Rare Diseases
Pogany	Gabor	European Organisation for Rare Diseases

2. Pharmaceutical industry*2.1. List in alphabetical order of representatives from the pharmaceutical industry*

Last name	First name	Institute or organisation of affiliation
Hughes-Wilson	Wills	Genzyme
Loth	Kevin William	Celgene
Parker	Samantha	Orphan Europe
Valenta	Barbara	Baxter

2.2. List in alphabetical order of alternates from the pharmaceutical industry

Last name	First name	Institute or organisation of affiliation
Fehervary	Andras C.	Novartis
Finck	Katia	Shire Human Genetic Therapies
Tellier	Zéra	LFB Biomédicaments
Zimmermann	Martine	Alexion Europe

3. Projects in the field of rare diseases financed by programmes of Community action in the field of health*3.1. List in alphabetical order of representatives from ongoing and/or past projects in the field of rare diseases financed by programmes of Community action in the field of health including three members of the pilot European Reference Networks on rare diseases*

Last name	First name	Institute or organisation of affiliation
Aymé	Ségolène	Orphanet Inserm

Last name	First name	Institute or organisation of affiliation
Donadieu	Jean	Hopital Trousseau
Donnai	Dian	European Network of Centres of Expertise in Dysmorphology
Fregonese	Laura	CHUV Lausanne
Garne	Ester	Hospital Lillebaelt-Kolding
Taruscio	Domenica	National Center for Rare Diseases at the Istituto Superiore di Sanità
Vives Corrons	Joan Luis	European Network for Rare Congenital Anaemias
Wagner	Thomas	European Centres of Reference Network for Cystic Fibrosis
Webb	Susan	Hospital de Sant Pau de Barcelona

3.2. *List in alphabetical order of alternates from ongoing and/or past projects in the field of rare diseases financed by programmes of Community action in the field of health*

Last name	First name	Institute or organisation of affiliation
Dubertret	Louis	Fondation Rene Touraine
Eleftheriou	Androulla Anastasiou	Thalassemia International Federation
Gatta	Gemma	Fondazione IRCCS, Istituto Nazionale dei Tumori
Kaminska	Magdalena	European Paediatric Hodgkin Network
Nelen	Vera	Provinciaal Instituut voor Hygiene
Nguyen	Gérard	Rett Syndrome Europe
Vittozzi	Luciano	Centro Nazionale Malattie Rare
Weill	Alain	European Haemophilia Consortium
Zeidler	Cornelia	Medizinische Hochschule Hannover

4. **Projects in the field of rare diseases financed by the Community Framework Programmes for Research and Technological Development**

4.1. *List in alphabetical order of representatives from ongoing and/or past projects in the field of rare diseases financed by the Community Framework Programmes for Research and Technological Development*

Last name	First name	Institute or organisation of affiliation
Blay	Jean-Yves	European Organisation for Research and Treatment of Cancer
Bushby	Kate	Institute of Human Genetics, University of Newcastle
De Baets	Marc	School for Mental Health and Neuroscience, Maastricht University
Hiort	Olaf	Universitätsklinikum Schleswig-Holstein
Koutouzov	Sophie	GIS-Institut des Maladies Rares
Wagemaker	Gerard	Department of Haematology, Erasmus University Medical Center Rotterdam

4.2. List in alphabetical order of alternates from ongoing and/or past projects in the field of rare diseases financed by the Community Framework Programmes for Research and Technological Development

Last name	First name	Institute or organisation of affiliation
Matthijs	Gert	Centre for Human Genetics, University of Leuven
Palau	Francesc	Centro de Investigación Biomédica en Red de Enfermedades Raras
Picci	Piero	Istituto Ortopedico Rizzoli di Bologna
Rieß	Olaf	Institute of Medical Genetics, University of Tübingen
Tanner	Stuart	Emeritus professor at University of Sheffield
Zambruno	Giovanna	Istituto Dermopatico dell'Immacolata, Roma