



Brussels, 3.9.2024
C(2024) 6017 final

COMMISSION DECISION

of 3.9.2024

appointing members of the Committee for Orphan Medicinal Products to represent patients' organizations, and repealing Decision C(2024) 3082

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THE EUROPEAN COMMISSION,

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

Having regard to Regulation (EC) No 141/2000 of the European Parliament and of the Council of 16 December 1999 on orphan medicinal products¹, and in particular Article 4(3) thereof,

Whereas:

- (1) The Committee for Orphan Medicinal Products (the 'Committee') consists of one member nominated by each Member State, three members nominated by the Commission to represent patients' organisations and three members nominated by the Commission on the basis of a recommendation from the Agency.
- (2) The term of office of the three members of the Committee representing patients' organisations expired on 30 June 2024.
- (3) The Commission launched a new public call for expression of interest on 26 October 2023 to select candidates to represent patients' organisations in the Committee and to establish a reserve list of candidates, to facilitate replacement of members of the Committee representing patients' organisations.
- (4) Based on a selection report, the Commission nominated three persons to represent patients' organisations: ISLA GOMEZ Julian, representing Dravet Syndrome European Federation, ALVES Inês, representing The National Association for Skeletal Dysplasias in Portugal, and DRIESSENS Mariette, representing Patient Alliance for Rare and Genetic Diseases in the Netherlands. It is therefore appropriate to appoint those persons as members of the Committee.
- (5) In accordance with Article 4(3) of the Regulation (EC) No 141/2000 members of the Committee are to be appointed for a term of three years. For reasons of clarity, it is appropriate to indicate the start date of the appointment.
- (6) Based on a selection report, the Commission selected three persons for a reserve list: NGUYEN Gerard, representing Rett Syndrome Europe and *Association Française du Syndrome de Rett*, CAVALLER Maria, representing EURORDIS-Rare Diseases Europe, TODOROVA-YANAKIEVA Yoana, representing RARE DISEASES BULGARIA. It is therefore appropriate to place those persons on a reserve list.
- (7) On 15 May 2024, the Commission adopted Decision C(2024) 3082² appointing persons representing patients' organisations as members of the Committee. However, that Decision wrongly indicated patients' organisations represented by the appointed

¹ OJ L 18, 22.1.2000, p. 1, ELI: <http://data.europa.eu/eli/reg/2000/141/oj>.

² Commission Decision C(2024) 3082 of 15 May 2024 appointing members of the Committee for Orphan Medicinal Products to represent patients' organisations.

members of the Committee. For reasons of clarity, it is appropriate to repeal and replace Decision C(2024) 3082.

HAS DECIDED AS FOLLOWS:

Article 1

The following persons are hereby appointed as members of the Committee for Orphan Medicinal Products for a term of three years as from 1 July 2024:

- (a) ISLA GOMEZ Julian, representing Dravet Syndrome European Federation;
- (b) ALVES Inês, representing The National Association for Skeletal Dysplasias in Portugal;
- (c) DRIESSENS Mariette, representing Patient Alliance for Rare and Genetic Diseases in the Netherlands.

Article 2

The following persons are hereby placed on a reserve list for appointment as members of the Committee for Orphan Medicinal Products:

- (a) NGUYEN Gerard, representing Rett Syndrome Europe and *Association Française du Syndrome de Rett*;
- (b) CAVALLER Maria, representing EURORDIS-Rare Diseases Europe;
- (c) TODOROVA-YANAKIEVA Yoana, representing RARE DISEASES BULGARIA.

Article 3

Commission Decision C(2024) 3082 is repealed.

Done at Brussels, 3.9.2024

For the Commission
Stella KYRIAKIDES
Member of the Commission