

Luxembourg SANTE.B.3/NL/HH/(2023)11454865

Dear members of the ERNs Board of Member States, Dear ERNs coordinators,

The first evaluation of the ERNs (¹) is now coming to an end. The exercise has been performed to evaluate the 24 European Reference Networks and 836 of their Healthcare Providers (HCPs) after the first 5 years of activity (2017-2021).

In September 2023, the Independent Evaluation Body appointed by the Commission, (the Consortium IDOM/ACSA) completed the final evaluation reports and submitted them to the Commission.

The Commission shared the final evaluation reports with the ERNs Board of Member States and invited them to take their decisions on the evaluation results during the 27th Board of Member States plenary meeting held on 24 October 2023 in Luxembourg.

Based on the Board of Member States decisions of 24 October 2023, I am pleased to announce the following final outcomes:

- a) All **24 Networks** obtained 'satisfactory' results. The networks are therefore maintained;
- b) **733 Healthcare Providers** (88% of assessed HCPs) obtained 'satisfactory' results. These HCPs are therefore maintained members of the ERNs;
- c) **71 Healthcare Providers** (8% of assessed HCPs) obtained 'needs improvement' and submitted an improvement plan. These will be re-evaluated in one year after the implementation of the plan, which they submitted to the Independent Evaluation Body.
- d) **25 Healthcare Providers** (3% of assessed HCPs) obtained either 'needs improvement' but did not submit an improvement plan (9 HCPS) or did not complete the self-assessment (16 HCPs). The membership of these HCPs was terminated;
- e) **1 Healthcare Provider** obtained needs improvement result and did not submit an improvement plan. An extension to submit the improvement plan by 13 November 2023 was decided by the Board of Member States. If submitted, the improvement plan will be reviewed and assessed by the Independent Evaluation Body prior to submitting the updated final report to the Commission on the 27th of November. The ERNs will also express its opinion about the improvement plan. The Board of Member States will then have two weeks to review the final report. A decision-

(1) As laid down in Article 14 'Evaluation' of the Commission Implementing Decision 2014/287/EU

making meeting of the Board of Member States will then be convened by DG SANTE for mid December.

f) **6 Healthcare Providers** (1% of the assessed HCPs) informed the Independent Evaluation Body of their decision to voluntary withdrawal.

In the attached annexes, you will find the list of HCPs falling under the categories c), d), e), and f).

I take the opportunity to thank all involved actors for their efforts and time dedicated to this evaluation process and to congratulate the ERNs and the Healthcare Providers of this overall successful result and important milestone. It has clearly shown the successful nature of the ERN system to further progress in their mission at the service of the patients living with a rare disease and their families.

We are proud to be with you and work together.

Yours faithfully,

Donata MERONI Head of Unit

Enclosure: List of HCPs falling under categories c), d), e) and f)