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EVALUATION, PUBLICATIONS

Hcéres evaluates the second French Rare Diseases Plan

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The 15 actions evaluated by Hcéres for the second French Rare Diseases Plan

In summer 2014, HCERES (then AERES) was commissioned by the Ministries for research and health to evaluate the research component of the 2011-2014 2nd French Rare Diseases Plan. At the same time, the French High Council for Public Health (HCSP) was entrusted with the treatment component of the Plan, and the two evaluations were carried out in a simultaneous and coordinated fashion.

The 15 actions evaluated included: changes to the evaluation and certification system for reference centres, the “Orphanet” information and research tool, the creation of a national research promotion organisation, the “Fondation maladies rares”, and the promotion of the development of therapeutic trials.

For the purposes of this task, Hcéres put together an international panel of independent experts, responsible for writing the evaluation report based on interviews, discussions and analysis of the literature. The goal was to measure results in terms of the fundamental knowledge acquired, progress in translational and clinical research, and advances in diagnostics. The panel heard the institutions and managers responsible for managing plan actions and stakeholders from the non-profit and business sector.

➤ [Télécharger le rapport d'évaluation \(encart télécharger en bas de page\)](#)

Find out more about the plan and monitoring system:

➤ [Plan national maladies rares 2011-2014](#)

➤ [Dispositif de suivi du plan national maladies rares](#)

FOCUS ON RARE DISEASES

A rare disease is an ailment affecting a small number of people, i.e. less than 1 in 2000 people, according to the European-wide threshold used.

In France, a disease is considered rare if less than 30,000 people have it. They affect 2 million people in France, and around 20 million in Europe.

[Sources: French Ministry of Social Affairs and Health](#) et [Orphanet](#)

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Rapport d'évaluation du Plan national maladies rares n°2 2011-2014

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