European Rare Diseases
Research Alliance

Resource on the State of the Art of Rare Disease Activities

2025 Report for Greece

National Mirror Group

Greece does not currently have a National Mirror Group (NMG) in place but an NMG is planned for launch in early 2026.

Contributors to the collection of data about rare disease activities in Greece are listed at the end of this report.

Definition of a Rare Disease

Greece adopts the formal European Union (EU) definition of a rare disease (i.e. those with a prevalence of no more than 5 patients per 10,000 persons. This definition is laid down in Regulation EC no. 141/2000 on Orphan Medicinal Products, Directive 2011/24/EU on Cross Border Healthcare as well as in the Council Recommendation on an action in the field of rare diseases of 8 June 2009.).

Status Quo of any National Plan or Strategy for Rare Disease

What is the status quo?

Greece has not adopted a National Plan or Strategy for rare disease. The reasons given for not adopting a National Plan or Strategy are lack of political appetite and no available funding. A National plan was developed 10 years ago but it was never adopted. Within the last two years, an updated proposal for a National Plan for rare disease was submitted to Greece's National Ministry of Health but no response to this proposal has been received.

Rare Disease Research Programmes and Funding

There are no specific funding calls or programmes for rare disease research in Greece.

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Rare Disease Registration and Biobanking

Greece has neither national nor regional registries for rare disease. However, there are plans underway to develop rare disease registries in Greece. There are disease-specific registries for rare conditions or groups of rare conditions in Greece such as Spinal Muscular Atrophy (SMA) and Cystic Fibrosis (CF). There is currently no centralised support for these registries from a funder, research body or health service.

There are no biobanks in Greece that include rare disease biosamples.

Organisation of Rare Disease Care

Centres of Expertise

There are 44 Centres of Expertise in Greece. There are Centres of Expertise for both specific rare diseases and groups of rare diseases. There is a national policy in place to designate Centres of Expertise. The following criteria is included within the policy to designate Centres of Expertise:

- Contribute to state-of-the-art research
- Bring together, or coordinate, multidisciplinary specialised medical and paramedical expertise such as physiotherapists, speech therapists, dieticians, genetic counsellors, etc
- Bring together, or coordinate, or liaise with social services or social workers, in order to serve the specific medical, rehabilitation and palliative needs of rare diseases patients
- Collaborate with patient organisations to bring in the patients' perspective]
- Provide education and training to healthcare professionals from all disciplines, including paramedical specialists and non-healthcare professionals (such as school teachers, personal/homecare facilitators) whenever possible
- Contribute to and provide accessible information adapted to the specific needs of patients and their families, of health and social professionals
- Participate in data collection for clinical research and public health purposes

ERNs

Greece is involved in multiple European Reference Networks (ERN). For the latest details on participating HCPs, click here.

Newborn Screening

33 conditions are included within Greece's Newborn screening (NBS) programme. Further information about which conditions are included in Greece's NBS programme can be found here. Greece's Ministry of Health makes decisions about which conditions are included within the programme.

Greece is involved in international initiatives about newborn screening decisions such as Screen4Care.

Diagnostics

A mix of public and private laboratories carry out genetic testing in Greece but there is no registry of where to find these laboratories. Genetic tests are not reimbursed in Greece. Genetic counselling is occasionally provided for patients with a suspected or confirmed rare disease but there are no policies or processes in place to ensure that this happens.

National Alliances of Rare Disease Patient Organisations

The National Alliance of Rare disease patient Organisations in Greece is Rare Diseases Greece. Further information about Rare Disease Greece can be found here.

Barriers identified by Greece's National Alliance that could prevent or restrict patient engagement include having no national rare disease research strategy, nor the political appetite to develop a strategy.

Information Resources for Rare Disease

National Orphanet Engagement

There is an operational national Orphanet team in Greece that is hosted by the ODIPY (National Organization for Quality Assurance in Health) and supported by Rare Diseases Greece. The team is funded by the host organisation, as well as from a small grant from the Ministry of Health. Rare Diseases Greece, on a voluntary basis, supports the Orphanet team.

Helplines

There is no helpline or information portal in place in Greece that's dedicated to rare disease.

Training and Education

There are no specific rare disease training activities in Greece.

Orphan Medicinal Products (OMPs)

50% of authorised OMPs by the EMA are available within Greece. There is an Early Access Programme/Expanded Access programme implemented in Greece.

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The Data Contributing Committee of Greece, which provided this 2025 data (correct as of the end of November 2025) in the context of the Resource on the State of the Art of Rare Disease Activities, is composed of the following individuals:

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