Resource on the State of the Art of Rare Disease Activities

2025 Report for Latvia

National Mirror Group

Latvia has a National Mirror Group (NMG), which was launched on 12th December 2024. The NMG is coordinated by Children's Clinical University Hospital. This NMG has overseen the collection of data from Latvia via a data contributing committee. Contributors are listed at the end of this report.

Definition of a Rare Disease

Latvia 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.). The National Plan espouses this definition. The definition often used in Latvia is that a rare disease affects 1 in 2,000 people.

Status Quo of any National Plan or Strategy for Rare Disease

What is the status quo?

Latvia has a National Plan for Rare Disease that is described as live, in-date and timebound. The current plan covers the period of 2023-2025. Prior to the current National Plan, there were two previous editions. The next edition of the plan is in development and will cover the period 2026-2027.

Elaboration and Adoption/How was the original plan elaborated?

Latvia's National Plan was prepared according to national regulations by the Ministry of Health (MoH). Organisations involved in the development of the plan include institutions with specific tasks, Health Care Professionals, National Health Service, university representatives, European Reference Network (ERN) representatives, scientists and patient organisations. In Latvia, public discussion of proposed national plans must take place, otherwise the plan cannot be approved. Latvia's National Plan for Rare Disease was approved by the Cabinet of Ministers.

Co-funded by
the European Union

ERDERA has received funding from the European Union's Horizon Europe research and innovation programme under grant agreement N°101156595.

The MoH is ultimately responsible for the National Plan but the plan was discussed widely by Latvia's National Mirror Group (NMG), which is composed of representatives from the Ministry of Health, National Alliance of Rare Disease patient organisations, patients and caregivers, Chief Specialist in Rare Disease, representatives from the rare disease coordination centre from Clinical University Hospitals, representative from the International Innovative Pharmaceutical Companies Association, and representatives from genetic laboratories (from University, Research centre and Children's clinical university hospital).

Is there funding for the Plan? How is it Implemented and/or Monitored or Evaluated?

There is no funding dedicated to Latvia's National Plan itself but there are funds dedicated to specific actions within the plan.

The same group responsible for the drafting and adoption of the National Plan is also responsible for implementing and overseeing Latvia's National Plan. The group was specifically established for Latvia's National Plan for Rare Disease and meets regularly.

Formal evaluation and monitoring of Latvia's National Plan for Rare Disease takes place. Latvia's Ministry of Health established a working group that met once or twice a year to discuss progress and current issues. These functions are now the responsibility of Latvia's NMG. The Ministry of Health is responsible for collecting information from all institutions on the implementation of the plan and, after the period defined in the plan, they are responsible for submitting a report to the Cabinet of Ministers.

Research in National Plans or national research strategies relevant to rare disease

Latvia's National Plan for Rare Disease does not specifically address rare disease research. The plan does include a task dedicated to Latvia's participation in ERDERA. The current National Plan was written before Latvia's NMG was set-up, but a similar working group was referenced and this working group has now been restructured into an NMG. The plan includes the following topics relevant to rare disease research:

- Rare Disease registry and newborn screening registry
- Biobanks/biosample catalogues for rare diseases
- Ontologies, codification or data standardisation e.g. participation in OD4RD project
- Diagnostics research ('solving unknown conditions') e.g. participation in JARDIN

The National Plan is hierarchically linked to Public Health Guidelines, where rare disease is identified as one of the priority areas. Measures related to rare oncological diseases are included in the oncology development plan. Efforts are made to ensure that actions included in different plans do not overlap, whilst promoting coordinated and consistent development of the healthcare sector.

Latvia's National Plan is aligned with documents developed by the EU and the WHO (World Health Organisation) in the field of rare disease.

Select Achievements of the National Plan

Below are three select achievements resulting from Latvia’s National Plan for Rare Disease:

1. Expansion of Latvia’s Newborn Screening programme
2. Improved access to molecular investigations
3. Improved access to Orphan drugs in Latvia

Rare Disease Research Programmes and Funding

There are no specific funding calls or programmes in Latvia to facilitate rare disease research, but rare disease projects are funded from general research programmes. At present, the Ministry of Health is working on defining the topics to be included in the national research programme ‘Public Health’ for 2026–2028. Proposals have been submitted to include the field of rare disease among the programme’s priority areas.

Rare Disease Registration and Biobanking

Latvia has a national registry dedicated to rare disease. The Rare Diseases Registry combines two registries: the Congenital Anomalies Registry and the Rare Diseases Registry, which are integrated within Latvia’s national Patient Registry Data (PREDA). The registry is hosted by the National Health Service, and the data is analysed by the Centre for Disease Prevention and Control (CDPC). Since the Rare Diseases Registry is integrated into the Congenital Anomalies Registry, it provides data on congenital anomalies, rare diseases, and conditions that are both rare and congenital. The importance of patient registration for shaping national health policy has been highlighted in Latvia’s National plans for rare disease.

The Rare Diseases Registry is a quantitative/statistical database. It contains information on patient identity, diagnosis codes, and where relevant, prenatal data. It does not include qualitative data, such as information on patients’ functional status, follow-up, or similar parameters. Aggregated statistical data can be obtained by any interested party upon request from the CDPC. As PREDA is linked to Latvia’s e-Health system, authorised healthcare professionals with access rights in e-Health can view individual patient data related to rare disease. The registry uses Orphacode and ICD10 coding systems.

There are also specific rare disease registries in Latvia. Theses registries are founded and curated by physicians dedicated to the relevant disease. They are not funded by NHS or MoH, but they may receive funding from international project grants.

Latvia does have a national biobank but it is not specifically or exclusively for biosamples relating to rare disease.

Organisation of Rare Disease Care

Centres of Expertise

Latvia has a national policy in place for designating Centres of Expertise for rare disease.

ERNs

Latvia is involved in multiple European Reference Networks. For the latest details on participating HCPs, click here.

Newborn Screening

22 conditions are included within Latvia's Newborn screening programme. They are: Phenylketonuria (PKU), Congenital Hypothyroidism (CH), Congenital adrenal hyperplasia (CAH), Galactosemia, Cystic Fibrosis, Biotinidase deficiency, Severe Combined Immunodeficiency (SCID), Spinal Muscular Atrophy (SMA), Glutaric aciduria type 1 (GA1), Glutaric acidemia type II (GA2), Medium-chain acyl-coenzyme A dehydrogenase (MCAD) deficiency, Long-chain 3-hydroxyacyl-CoA dehydrogenase (LCHAD) deficiency, Very long-chain acyl-CoA dehydrogenase (VLCAD) deficiency, Primary carnitine deficiency, Carnitine–acylcarnitine translocase deficiency, Carnitine palmitoyltransferase deficiency type I (CPT I), Carnitine palmitoyltransferase deficiency type II (CPT II), Arginemia, Citrulinemia type 1, Adenylosuccinate lyase (ADSL) deficiency, Homocystinuria (HCU), and maternal B12 deficiency.

Diagnostics

In Latvia, the majority of genetic tests are reimbursed by the National Health Department. Diagnostic testing is organised into two main categories: tests performed in Latvia and tests performed abroad (both partially and fully). There is an allocated budget and procedure to follow based on test type. If the genetic test is available in Latvia, it must be performed in a designated laboratory. Reimbursement is ensured by specific manipulation codes that are made by the laboratory and confirmed by the NHS. Tests that are not performed in Latvia (mainly due to technological and quality restrictions), can be performed abroad following a decision by the Rare Disease Consilium, and only in a laboratory that has a signed an agreement after following a procurement procedure. Latvia's national plan includes provisions for ensuring specific examinations abroad, which are implemented when appropriate funding is available. It also includes measures to promote the participation of national specialists in European Reference Networks (ERNs) in order to strengthen international collaboration and access to expertise in the field of rare disease.

Latvia is involved in JARDIN and will run a pilot project on undiagnosed diseases within Latvia.

There is a policy in place in Latvia to ensure national providers provide genetic counselling for those with a suspected or confirmed rare disease.

National Alliances of Rare Disease Patient Organisations

Latvijas Reto slimību alianse is Latvia’s National Alliance of Rare Disease patient organisations. Further information can be found here.

Information Resources for Rare Disease

National Orphanet Engagement

Latvia has an operational Orphanet team hosted by the Children' s Clinical University Hospital. The team is entirely funded by the host organisation.

Helplines

A national helpline/information portal for rare disease does not currently exist in Latvia. However, Latvia’s current National Plan includes an action to assess the feasibility of launching a helpline/information portal for rare disease. Opportunities to develop and implement the helpline are being evaluated for inclusion in the 2026–2027 National Plan.

Training and Education

Training activities in rare disease are available in Latvia. Training for specialists in the field of rare disease is not currently regulated. Rare disease topics are included in some university courses but there is no dedicated course for rare disease. Education in the field of rare disease can also take place as part of medical professionals’ recertification process, although participation is voluntary. There are also training activities organised by the Latvian Association of Rare Disease Specialists. Rare disease topics are also included in broader medical conferences. Rare disease centres established at clinical university hospitals also carry out public awareness activities in the field of rare diseases, including the Rare Disease Forum. The target audiences of these events vary. There are events aimed at both rare disease patients and healthcare professionals. Some training opportunities are free of charge, whilst others are paid. Information and training materials are available in Latvian.

Orphan Medicinal Products (OMPs)

Of the OMPs given EMA registration between 2015-2024 (according to the IQVIA WAIT indicator), 13 OMPs are available on the compensation list in Latvia.

Compassionate use programs are available in Latvia but the process to access treatments is lengthy, compared to other countries.

Latvia is not involved in any formal efforts or initiatives with other countries to support access to medicines and therapies for rare diseases, but Latvia has been part of joint Baltic vaccine procurements.

ERDERA
European Rare Diseases
Research Alliance

Disclaimer: The data collection activities which enabled this 2025 national report were supported by the ERDERA. ERDERA has received funding from the European Union's Horizon Europe research and innovation programme under grant agreement N°101156595. Views and opinions expressed are those of the author(s) only and do not necessarily reflect those of the European Union or any other granting authority, who cannot be held responsible for them, nor should this document be viewed as an official national 'position'.

Co-funded by
the European Union

The Data Contributing Committee of Latvia, 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:

- Madara Auzenbaha, Children's Clinical University Hospital, Riga Stradiņš university,
- Gita Tauriņa, Children's Clinical University Hospital
- Baiba Ziemele, Latvia Hemophilia Society
- Juris Beikmanis, Latvian Rare Disease Alliance.
- Zane Reinholde, Ministry of Health