European Commission

European Reference Networks

Working for patients with rare, low-prevalence and complex diseases

Share.Care.Cure.

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The EU stands with rare disease patients to bring them help, hope and a brighter future

Sandra Gallina
Director General DG SANTE

While these diseases may be rare, they impact numerous individuals and present many similar challenges. Having a rare disease may mean that you have a condition that your doctor or other healthcare professional cannot identify. It may also lead to symptoms being misdiagnosed—sometimes for years—during which your condition may worsen. Often, having a rare disease means not knowing what is wrong or how to alleviate pain and discomfort. It can be frustrating, lonely, and at times, feel hopeless.

The EU has long recognized the importance of addressing rare diseases, taking significant action in terms of financial commitment and areas of work to promote research, improve access to diagnosis and treatment, enhance patient care, and support the development of new treatments, known as 'orphan drugs.'

For millions living with rare diseases, scientific progress alone is not enough. What is equally needed is a coherent regulatory and policy framework that allows innovation to swiftly move from research to approval and into patient care. First, we want to help patients get the accurate diagnosis they need. Then, we want to ensure they receive treatment and care to minimize discomfort and help them live as fully as possible. Lastly, we aim to collaborate to find cures.

The European Commission has supported numerous actions in public health and healthcare systems to help Member States develop national responses, strategies, and plans. These include the European Reference Networks (ERNs), which began their work in March 2017.

ERNs are cross-border virtual networks that bring together European hospital centres of expertise to tackle rare, low-prevalence, and complex diseases requiring highly specialized healthcare. By connecting healthcare providers, researchers, and patient organizations, ERNs leverage European collective expertise to ensure no patient is left behind, regardless of where they live or how rare their condition is. They represent one of the greatest achievements of the rare disease community in Europe and have become an inspiration for global action.

Through these networks, experts reach the patient, eliminating the need for patients to travel far. The European Union connects the dots, maximizing synergies between Member States and encouraging the sharing of knowledge and resources.

ERNs pave the way for clinical studies and test therapeutic interventions, putting them at the forefront of innovation in numerous rare disease fields. Their additional value lies in overcoming traditional barriers in healthcare. By using the Clinical Patient Management System 2.0 (CPMS), an advanced IT platform for cross-border medical discussions, ERNs enable expert teams to collaborate on patient cases, offering advice on diagnosis and treatment that might otherwise be inaccessible in a patient's home country.

> *The European Commission has demonstrated* ***a steadfast, 25-year commitment*** *to rare diseases by building a cohesive framework of* ***targeted legislation****, cross-border* ***expert networks*** *(ERNs), and massive* ***research investment*** *to ensure no patient is left behind in the European Health Union.*

Moreover, ERNs are transforming the research landscape for rare diseases, accelerating innovative therapies, contributing to clinical trials, and advancing the understanding of rare conditions. Initiatives like the EU Biotech Act further support translating breakthrough science—including gene, cell, and enzyme therapies—into clinical practice, especially for rare diseases where traditional development models fall short.

Equally important is the role of ERNs in empowering patients and their families. Through collaboration with patient advocacy groups, ERNs ensure that the voices of patients and their families are heard.

Five years after the establishment of the ERNs, in December 2022, the Commission launched the first evaluation of the ERNs. An independent evaluation body assessed the 24 ERNs and the 836 clinical centres that joined in 2017. The results showed that all 24 ERNs and 799 (95%) of the clinical centres met the evaluation criteria, demonstrating a strong commitment to improving care for people with rare diseases and contributing effectively to patient care.

Ongoing actions in rare diseases include:

- Improving access to safe, effective, and affordable medicines, including 'orphan medicines,' via the revision of EU Pharmaceutical legislation. The new legislation aligns incentives for therapies addressing unmet needs, including ultra-rare diseases, and promotes adaptive, predictable regulatory pathways.
- Promoting better cross-border access to health data from rare disease patients via the European Health Data Space Regulation, effective from 26 March 2025.
- Implementing Europe's Beating Cancer Plan, launched on 3 February 2021, which tackles paediatric cancers, complementing actions by the European Reference Networks focused on rare cancers: ERN EURACAN (rare adult solid cancers) and ERN PaedCan (paediatric cancer [haemato-oncology]).
- Reinforcing the work of 24 ERNs via grants worth EUR 77.4 million, approximately EUR 3.2 million per ERN, supporting work until September 2027 on consultations, patient registries, training, clinical practice guidelines, and communication activities.
- Improving ERN integration into national health systems and developing national plans via the Joint Action JARDIN, funded with EUR 18.75 million.

Future years will see the consolidation of the ERNs, increasing coverage in Member States, particularly those with fewer ERNs, and further embedding of ERNs into national healthcare systems. We anticipate impactful ERN actions enhancing care for patients with rare diseases, expanding registries, and disseminating rare disease knowledge.

The call for greater European coordination in health is growing, and the Commission's proposal to build a robust European Health Union reflects this desire. A strong European Health Union guarantees timely diagnosis, access to expertise, innovation, and equitable care for those with rare diseases, regardless of where they reside.

The next stage of network development should harness the drive for better patient outcomes and greater cross-border healthcare cooperation. Living with a rare disease should not mean uncertainty about diagnosis, care, and treatment, nor should it mean facing it alone.

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Background: rare diseases

According to the latest review by Orphanet, the 24 European Reference Networks cover about 92% of the 6 246 classified rare diseases, or approximately 5,800 in all. This leaves about 7.5%, or an estimated 470, currently uncovered. DG SANTE is sharing this information so that EU citizens can easily see which diseases are covered, and by which European Reference Network. There are an estimated 6,000 to 8,000 distinct rare diseases, but not all of them have been classified to date.

In the field of oncology alone, for example, there are almost 300 different types of rare cancers and each year more than half a million people in Europe are diagnosed with one of them.

Many of those affected by a rare or complex condition do not have access to diagnosis and high-quality treatment. Expertise and specialist knowledge may be scarce because patient numbers are low.

The EU and national governments are committed to improving the recognition and treatment of these rare and complex conditions by strengthening European-level cooperation and coordination and supporting national plans for rare diseases.

The Directive on Patients' Rights in Cross-border Healthcare[1] not only enables patients to be reimbursed for treatment in another EU Member State but also makes it easier for patients to access information on healthcare and their treatment options.

The Directive became law in EU Member States in 2013 and laid the foundations for cross-border collaboration in areas such as rare diseases and ERNs or eHealth.

Against this background, with the support of the EU Health Programmes, the 24 European Reference Networks began their work in March 2017, comprising at the time 956 highly specialised centres. Since then, thousands of patients with rare or complex diseases have been helped by the programme, and today the ERNs have grown to include 1,606 specialised centres based in 375 different hospitals spread across all 27 EU Member States and Norway.

1 Directive 2011/24/EU of the European Parliament and of the Council of 9 March 2011 on the application of patients' rights in cross-border healthcare, OJ L 88, 4.4.2011, pp. 45–65

Part 1: The European Reference Network: An overview of the system in place

What are European Reference Networks?

European Reference Networks (ERNs) are cross-border virtual networks that bring together European hospital centres of expertise and reference to tackle rare, low prevalence and complex diseases and conditions requiring highly specialised healthcare.

No country alone has the knowledge and capacity to treat all rare and low prevalence complex diseases. ERNs enable patients and doctors across the EU to access the best expertise and timely exchange of life-saving knowledge, without having to travel to another country. The networks make it easier to share rare disease experience and knowledge with member hospitals, researchers, and patient groups.

ERNs help raise both public and professional awareness of rare diseases and their often-complex symptoms, making early and accurate diagnosis — and timely access to effective treatment — more likely. They provide a shared platform where experts can create guidelines, deliver training and exchange knowledge. By pooling data from many patients across Europe, ERNs can also support large clinical studies that deepen

understanding of rare conditions and speed up the development of new medicines.

Patient involvement differs across Networks, but all ERNs include patient representatives in key activities such as drafting clinical guidelines, designing care pathways and contributing to clinical research. And some ERNs even include them in their governing/management boards.

For specialist health professionals, ERNs offer a unique chance to connect with peers across the EU and Norway, reducing the professional isolation that many experts in rare diseases experience. The system is driven by innovation, encouraging new models of care and transforming how treatments are delivered through eHealth tools, virtual consultations and emerging medical technologies. ERNs act as incubators for digital health services and telemedicine.

They also help healthcare systems work more efficiently by creating economies of scale and making better use of resources, strengthening the long-term sustainability of national systems. Above all, ERNs are a clear example of how European solidarity can deliver real benefits for patients and professionals alike.

To review a patient's diagnosis and treatment, ERN coordinators convene 'virtual' advisory panels of medical specialists across different disciplines, using a dedicated IT platform – the Clinical Patient Management System (CPMS 2.0). Discussions are carried out in the CPMS allowing healthcare providers from all over the EU to work together online to discuss, diagnose and treat patients with rare, low prevalence and complex diseases. ERNs also coordinate and facilitate educational and training activities, develop clinical practice guidelines and other clinical decision support tools, work together on knowledge generation and dissemination through communication activities, and serve as focal points for research and innovation around rare and low prevalence complex diseases. In addition, ERNs are populating EU-registries with high quality data from patients with rare diseases, creating a unique, highly valuable data source to foster research and devise the next generation of treatments for rare and complex diseases.

From their beginning in March 2017, the network has grown to 24 ERNs comprising 1,606 specialised centres based in 375 different hospitals spread across all 27 EU Member States and Norway. These ERNs work on a range of thematic areas, from rare bone disorders and childhood cancers to rare vascular diseases, benefitting thousands of EU patients suffering from a rare or complex health condition.

The ERN initiative receives support from the EU funding. EU Member States lead the ERN process: they are responsible for recognising centres at national level and endorsing applications. A Board of Member States (BoMS) is responsible for developing the EU ERN strategy and approving the creation of networks and inclusion of new members.

The 24 ERN coordinators collaborate within the ERN Coordinators group (ERN-CG), which was set up in 2017. This strategic group establishes a common ground on several key technical and organisational aspects of the ERNs. The ERN-CG and the BoMS are involved in the five working groups officially designated, dealing with topics such as knowledge generation; monitoring; improvement of the evaluation; ethical, legal and social implications; management activities.

Establishing a European Reference Network

The EU legislation sets the process and criteria for establishing an ERN and selecting its members. Let's see what it takes to become an ERN.

Commission Delegated Decision 2014/286/EU[2] sets the criteria and conditions that ERNs and healthcare providers must fulfil. It defines, among others:

- Requirements for membership,
- Governance rules,
- Conditions for involvement of clinical and patient representatives,
- Quality and expertise standards.

Commission Implementing Decision 2014/287/EU[3] sets the procedures for:

- Establishing ERNs,
- Approving new members of an existing ERN,
- Evaluating Networks and their members,
- Organising the independent assessment process.

An ERN must meet the following criteria:

- have at least 10 healthcare providers (network members) from at least 8 different EU countries
- each healthcare provider (network member) must be endorsed by their respective EU country
- all members must have common expertise in a specific field, treatments, diseases or health conditions
- submit a proposal for a network (once the call for ERN is launched)
- meet the criteria for networks and their members, as in the ERNs Commission delegated decision
- gain the approval for membership, which the Board of Member States grants based on the independent technical assessment.

Countries which do not have representation in an approved ERN may participate through healthcare providers designated by their Member State as 'associated partners'. They have access to good practice guidelines for diagnosis, care and treatment, and are involved with research activities.

The European Commission ran a first call for proposals for members for ERNs in 2016. The ERN Board of Member States approved the first 23 networks in December 2016 and February 2017.

The Commission issued the first call for proposal for new members to join the existing 24 ERNs in 2019. On 26 November 2021, the ERN Board of Member States approved 620 applicants by consensus.

2 European Commission, Delegated Decision 2014/286/EU of 10 March 2014 setting out criteria and conditions that European Reference Networks and healthcare providers wishing to join a European Reference Network must fulfil, OJ L 147, 17.5.2014, pp. 71–78

3 European Commission, Implementing Decision 2014/287/EU of 10 March 2014 setting out criteria for establishing and evaluating European Reference Networks and their Members and for facilitating the exchange of information and expertise on establishing and evaluating such Networks, OJ L 147, 17.05.2014, pp. 79–87

Governance structure: Member States and the ERNs

by Professor Birutė Tumienė,
Co-Chair of the Board of Member States of the ERNs

There are currently 1 606 specialised centres located in 375 hospitals of 27 EU Countries and Norway, a number which is expected to rise even further following a proposed call for affiliated partners to be launched in 2026. That's good news for patients, who will have greater access than ever before to highly specialised healthcare services, and for clinicians, who benefit from collaboration with other experts across the EU and Norway.

As the European Reference Networks (ERNs) expand in size, scope and ambition, their success increasingly depends on strong coordination and effective partnership across the entire system. This is where the Board of Member States (BoMS) plays a pivotal role.

Established on 5 February 2014, the Board brings together officially nominated representatives from every EU Member State and Norway and acts as the central decision-making body guiding the strategic development of the ERN system. From the earliest stages, the Board has overseen the transition of ERNs from concept to reality, approving the first Network proposals and their healthcare provider memberships when the ERNs were launched in 2017.

The BoMS is responsible for all major decisions shaping the evolution of the Networks. It approves new ERNs and evaluates applications from healthcare providers wishing to join an existing Network. It also has the authority to decide on the termination of an ERN, the loss of membership of individual centres, and the adoption of improvement plans following periodic evaluations.

These responsibilities ensure that ERNs maintain high standards of clinical excellence, governance and equity across all participating countries.

Close cooperation between the BoMS and the ERN Coordinators' Group (ERN-CG) is essential to the system's functioning. The ERN-CG — whose members are endorsed by the Board during the original ERN selection process — works on the operational and strategic aspects of implementation, governance and performance.

While the BoMS sets the strategic framework and validates key decisions, the ERN-CG ensures that Networks operate consistently, efficiently and in alignment with common priorities. Together, the two bodies form a joint leadership architecture: one grounded in Member State authority, the other in clinical and organisational expertise.

This collaborative structure has become even more important since the ERNs entered a new phase of integration within the national health systems with the March 2024 launch of the Joint Action JARDIN (https://jardin-ern.eu/)

This work aims to ensure that ERN expertise becomes increasingly embedded in everyday clinical practice, improving access to specialised knowledge for patients across the EU/EEA.

The envisaged expansion of the ERNs will bring enormous opportunities but also new demands for coordination, oversight and long-term planning.

The BoMS will continue to act as guardian of the system's integrity, ensuring equal participation of Member States, safeguarding quality, and steering the Networks through each stage of their evolution. As ERNs mature, the partnership between the Board of Member States, the Coordinators' Group and the European Commission will remain essential to achieving a fully integrated, sustainable and impactful rare disease ecosystem in Europe.

Work of the European Reference Networks

European Reference Networks (ERNs) bring together top medical specialists from many countries to help diagnose, treat and support people living with rare and complex diseases. No single country has experts for all rare conditions — but together, Europe does. ERNs make this expertise available to everyone, wherever they live. Let's see what they are working on.

Provide expert advice across borders

Doctors facing difficult or rare cases can ask ERN specialists for help through a secure online system called the Clinical Patient Management System (CPMS 2.0).

Experts from different countries review the case together and give advice on diagnosis or treatment. This means patients can benefit from international expertise without having to travel.

Create better guidelines for care

ERNs create and update Clinical Practice Guidelines — documents that explain the best ways to diagnose and treat specific rare diseases.

By agreeing on common standards, ERNs help ensure that people across Europe receive the same high-quality care.

Training for Health Professionals

ERNs organise webinars, courses, workshops, and clinical exchanges to train doctors, nurses and other professionals.

This helps make rare-disease knowledge more widely available and improves care even in countries with few specialists.

Building Rare Disease Registries

ERNs collect information (with patients' consent) in disease registries.

Registries help doctors and researchers understand how rare diseases develop, which treatments work best, and where care can be improved.

They also support research and the development of future medicines for rare disease patients (orphan drugs).

Raising Awareness and Sharing Information

ERNs create websites, leaflets, videos, webinars and awareness campaigns so that patients, families and professionals can learn about rare diseases and where to find expert help.

Clear information helps shorten the road to diagnosis and improves daily support for patients.

Affiliated Partners

ERNs aim to deliver genuine added value to all EU Member States. The relevant legislation enables countries without representation in an ERN to participate through healthcare providers that are designated by their Member State as 'associated' and/or 'collaborative' national centres. Member States may also wish to designate a national coordination hub to liaise with all ERNs. Collectively, Associated National Centres, Collaborative National Centres and National Coordination Hubs are referred to as Affiliated Partners

The ERN Board of Member States sets up the common framework for the designation and integration of these types of centres into the ERNs. Nevertheless, it is essential that the designation of Affiliated Partners by Member States be undertaken through open, transparent and robust procedures, and all ERNs must have in place a clear policy objective for the active engagement and participation of Affiliated Partners. As of December 2025, the ERNs are made of 1 606 health care providers, of which 191 are Affiliated Partners.

The Working Groups of the European Reference Networks

The ERNs Coordinators Group (CG) or the Board of Member States (BoMS) may decide to set up Working Groups (WGs) to carry out specific tasks of interest, as envisaged by Article 9 of the Rules of Procedure of the ERNs CG and by Article 13 of the Rules of Procedures of the BoMS.

Each WG is led by a Chair, who may be an ERN Coordinator, a Board of Member States representative, or a Commission representative.

Currently, there are several Working Groups addressing the following topics:

- Ethical, Legal and Social Implications issues
- Knowledge generation and capacity
- Management activities
- Monitoring
- The improvement of the ERN evaluation

There are also other working groups at ERN level or inter-ERN level, addressing specific topics such as transition of patients from paediatric to adult care, pregnancy and family planning, the ERN registries.

More detailed information regarding their composition can be found at the following link: https://health.ec.europa.eu/document/download/de4a32c7-3c51-4c80-9aa4-c5df0a2d2670_en?filename=ern_working-groups_overview_en.pdf

The role of patients' organisations

ERNs are about patients. Patient organisations have played an active role in the development of the networks for more than a decade. Collectively, they have helped ensure that ERNs prioritise enhancing clinical excellence and improving patients' health outcomes, while ensuring equitable access to quality care across Europe.

The involvement of patient advocates through the European Patient Advocacy Groups (ePAGs) has been central from the earliest stages of the ERN initiative. Patient representatives played a formative role in shaping the original concept within the High-Level Working Group on Health Services and Medical Care and supported its translation into the Cross-Border Healthcare Directive. They accompanied Member States and the European Commission throughout the entire journey: from defining the legislative basis for ERNs, to mobilising and clustering expert clinical leaders, and ultimately to the creation of the 24 Networks grouped by therapeutic area.

Today, ePAG advocates continue to work hand in hand with clinical leads and ERN coordination teams, actively contributing to the implementation and ongoing development of the Networks. Their involvement extends across a wide range of core activities, including participation in working groups, reviewing clinical practice guidelines, co-designing care pathways and supporting the development of outcome measures that reflect what matters most to patients. In many ERNs, ePAGs also contribute to the design of training initiatives, awareness-raising activities and communication materials that help patients and professionals better understand rare conditions and available expertise.

As key partners in nurturing the long-term vision behind the ERNs, ePAGs help ensure that the patient perspective is systematically integrated into governance and decision-making. They collaborate with clinical experts and ERN management teams to highlight unmet needs, identify service gaps and bring forward priorities that may otherwise remain invisible. Their lived experience provides essential insights into the quality of care, diagnostic pathways, psychosocial needs and barriers to accessing expertise. This perspective is increasingly recognised as indispensable for shaping patient-centred services and ensuring that ERN activities meaningfully address the realities of living with a rare disease.

Looking ahead, ePAGs could play an even broader role in strengthening the ERNs. They could support the harmonisation of patient information materials across Europe, help co-develop digital tools for shared decision-making, contribute to the definition of patient-reported outcomes, and promote the inclusion of diverse patient communities in research and clinical studies. ePAG advocates could also help Member States integrate ERN expertise into national care pathways, facilitate peer-support networks, and contribute to awareness campaigns aimed at earlier diagnosis. By engaging more systematically in monitoring and evaluation activities, ePAGs could help assess whether ERN services respond to patient needs and propose improvements based on direct feedback from the community.

Leading a European Reference Network

by Professor Ruth Ladenstein,
Chair of the Coordinators' Group Trio

Coordinating an ERN involves guiding a pan-European community of specialists, managing complex clinical and organisational tasks, and ensuring patients benefit from the best expertise available across the EU.

Coordinating a European Reference Network (ERN) is a complex, highly demanding role that requires scientific leadership, organisational skill and a deep commitment to improving the lives of people living with rare and complex diseases. At its core, ERN coordination requires the ability to unite dozens of specialised centres across Europe into a coherent community that works collaboratively rather than in isolation. The coordinator must create the conditions for experts from different countries, cultures and health systems to exchange knowledge, develop common standards of care and jointly tackle clinical challenges that are too rare or too complex to be addressed at national level alone.

Building and maintaining such a network involves strategic planning, meticulous management and continuous communication. Coordinators must guide large multidisciplinary teams, mobilise clinical experts, and ensure that patient representatives are fully integrated into decision-making. They are responsible for designing the scientific and clinical priorities of the network, overseeing the development of clinical guidelines, care pathways and training programmes, and ensuring that members work towards shared objectives. As ERNs expand, coordinators must also adapt governance structures, strengthen management teams and secure adequate resources to sustain the network's growing responsibilities.

The position also requires strong engagement with EU institutions and national healthcare authorities. Coordinators must navigate regulatory frameworks, ensure alignment with EU policies and support the integration of ERN activities into national health systems. They play a key role in promoting the use of digital tools — from virtual case discussions to cross-border data sharing and the management of disease registries — which are essential for enabling experts across the EU/EEA to work together effectively.

Coordinators also help members connect with research infrastructures, identify opportunities for joint studies and clinical trials, and encourage innovation in diagnostics, treatments and care models. They must balance the scientific aspirations of the network with the practical needs of clinicians and the lived experiences of patients.

Above all, coordinating an ERN demands vision and long-term thinking. It means guiding the network through phases of growth, adapting to evolving expectations and ensuring that the collective expertise of the network translates into tangible improvements for rare disease patients across Europe. It is a responsibility that requires resilience, diplomacy and creativity — and when successful, it demonstrates how shared expertise and solidarity can transform care for some of Europe's most vulnerable patients.

Communication activities

Communicating clearly and proactively on rare diseases is not only a strategic duty – it is a moral and social responsibility. Raising awareness of the European Reference Networks (ERNs) is also an important task. DG SANTE, together with the individual networks, work to ensure that all relevant stakeholders are informed about the ERNs.

The complexities of rare diseases and the limited availability of expertise make it essential that all stakeholders – patients, clinicians, researchers, national authorities, industry and payers – understand both the challenges and the solutions offered at EU level.

The European Reference Networks (ERNs) are a key instrument to address these challenges. By connecting specialised centres across Member States, they pool scarce expertise, provide cross-border consultations, develop clinical guidelines and support registries and research. Yet their value can only be fully achieved if stakeholders know how to access and contribute to them. Targeted communication helps bridge this gap.

For patients and families, it enables visibility, reduces isolation and directs them towards the centres of expertise able to support their condition. For healthcare professionals, it clarifies referral pathways, promotes training opportunities and encourages participation in ERN activities.

Ultimately, communication is not a secondary activity – it is the catalyst that transforms networks into accessible knowledge and hope into measurable progress.

At EU level, DG SANTE provides overarching visibility for the 24 ERNs by producing core communication materials such as factsheets, infographics and explanatory resources, as well as dedicated webpages. These materials help relevant stakeholders - especially patients and carers - understand how the ERNs operate.

DG SANTE also promotes the ERNs within the wider context of cross-border healthcare, regularly highlighting the availability of the ERNs, the access to expert care through virtual consultations, and the principle that expert knowledge should be available to patients regardless of their location.

In parallel, each ERN is responsible for raising awareness of its own medical domain and network activities. The ERNs manage their internal communication so that the professionals within their member institutions are well informed and benefit from being part of the network. Externally, the networks share information about their expert centres, educational opportunities, research and other relevant developments to support patients, clinicians and the wider rare disease community.

Collaboration between the ERNs also plays an important role. Communication managers from across the networks share best practices and work together to raise awareness of the ERNs in general. These combined efforts strengthen visibility of the ERNs and enable patients with rare and complex conditions across Europe to access the best possible care when they need it most.

DG SANTE has a dedicated website on rare diseases and the ERNs, https://health.ec.europa.eu/rare-diseases-and-european-reference-networks_en, which includes, among other resources, links to videos produced by the ERNs on rare disease patients' stories and rare disease patient advocates

The Clinical Patient Management System

Online platforms are essential for fostering pan-European collaboration in specialised healthcare. The European Reference Networks (ERNs) are interconnected through the Clinical Patient Management System (CPMS) - a dedicated and highly secure IT platform, now in its second generation (CPMS 2.0). This web-based clinical application is a cornerstone of the ERN framework, empowering healthcare providers across the European Union to collaborate remotely on the diagnosis and treatment of rare, low prevalence and complex diseases. To further enhance accessibility, the platform is also available via dedicated mobile applications for both Android and iOS.

The CPMS 2.0 enables networks to convene online advisory boards composed of medical specialists from different Member States. These boards securely review patient cases to reach expert consensus on diagnosis or therapeutic strategies.

This capability has fundamentally transformed the handling of rare diseases - clinicians who previously worked in isolation can now seamlessly consult peers, obtain second opinions, and leverage a vast collective of specialised knowledge.

A foundational principle of the CPMS 2.0 is its unwavering commitment to data security and patient privacy. By integrating advanced video conferencing and secure data-sharing capabilities, the platform ensures that physical geography no longer hinders the much needed multidisciplinary, remote teamwork. The platform also facilitates the secure exchange of high-resolution medical imaging, such as digital pathology slides and radiology scans.

Beyond immediate clinical care, and subject to additional explicit patient consent, this data can contribute to longitudinal research and clinical education.

The CPMS 2.0 strictly adheres to all relevant European and national legislation on data protection, including the General Data Protection Regulation (GDPR). This rigorous legal framework ensures that all patient data is processed with the highest standards of confidentiality and security.

However, it is important to emphasise that while the treating physician retains fully clinical responsibility for the clinical care and management of their patient. The platform functions as a powerful enabler of expert consultation, rather than a replacement for the primary care relationship.

The CPMS 2.0 codebase will be distributed under an open-source license, free of charge. This will allow the platform to be adapted for use beyond rare diseases, offering a ready-made solution for other national or European health networks seeking to implement structured remote consultation.

The Continuous Monitoring and Quality Improvement System

A robust and continuous monitoring system has been established as a cornerstone for building a comprehensive quality improvement framework.

The continuous monitoring of the European Reference Networks (ERNs) is conducted through a single annual data collection that runs from January to March, covering the full activity period from January to December of the previous year. The indicators collected are precisely defined in the ERN data collection manual.

This framework is fundamental to developing a quality improvement system, measuring appropriate outcomes for the ERNs, identifying areas of success and potential challenges, and ultimately, to demonstrating the ERNs' added value.

Crucially, the goal is not to compare ERNs against each other, but to track the progress of each individual ERN over time.

The First Monitoring report of the ERNs, published in November 2025, compiles the data reported to the Commission through regular collection exercises. It presents this information both per ERN, and in the form of country profiles, which include a statistical overview of each country's participation. This marks the first time a monitoring report on ERN activity has been produced for public release.

The data collected is based on a set of 24 indicators covering the seven core areas of the ERNs' work: coordination, dissemination, evaluation, Healthcare and Clinical Patient Management System (CPMS 2.0), registries, training and education, clinical practice guidelines and other clinical decision support tools.

With these monitoring reports, the Commission offers valuable insights into the impact of the networks, their activities, and the concrete benefits they provide for patients and families affected by rare diseases.

The report was produced to showcase the growth and professionalisation of the ERNs. Moreover, the publication of this data provides an understanding of the different areas of work, their reach, impact and added value for patients leaving with rare diseases and their families. The report also incorporates feedback received from the ERN Coordinators.

First Monitoring report of the European Reference Networks (ERNs), available on:
https://health.ec.europa.eu/publications/european-reference-networks-monitoring-report-2025_en

Evaluation of the European Reference Networks

The European Reference Network's (ERNs) legal framework establishes that all ERN Networks and their Members shall be periodically evaluated, at the latest every five years after their approval or after the last evaluation.

The evaluation must be performed by an independent evaluation body (IEB) appointed by the Commission to ensure that ERNs and their members meet agreed-upon standards and evaluation criteria and whether they help improve rare disease patient care in Member States.

The Commission launched the first evaluation of the ERNs in December 2022 to verify and assess:

- the fulfilment of the criteria and conditions in Delegated Decision 2014/286/EU
- the accomplishment of the objectives of Article 12(2) of Directive 2011/24/EU
- the network's outcomes and performance and each member's contribution

Over 10 months, the IEB evaluated all 24 ERNs and 836 Clinical Centres which joined in 2017. The assessment included self-evaluations, document reviews, interviews, and on-site audits. The Clinical Centres that did not meet the required conditions had to submit and implemented improvement plans and were re-evaluated a year later.

All ERNs and 799 Clinical Centres out of 836 (95.6%) achieved a satisfactory evaluation outcome, demonstrating a strong commitment to improving care for people with rare diseases. This means that all ERNs and vast majority of evaluated Clinical Centres are meeting expectations and contributing effectively to patient care.

Some clinical centres did not meet the evaluation criteria and either did not take corrective action or chose to leave. 37 Clinical Centres (4.4%) were removed or withdrew from the ERN system, for reasons such as not completing the evaluation, not submitting an improvement plan, failing the re-evaluation or voluntary withdrawal.

ERNs performed especially well in:

- Education and training: this was the top-scoring area, showing strong commitment to teaching and sharing expertise.
- Networking and dissemination: ERNs are good at connecting experts and spreading knowledge.
- Governance: many ERNs have solid structures for coordination, often including patient representative's work.
- Research contributions: many ERNs excel at building ERN common registries, facilitating data sharing which helps to advance research on rare or complex diseases.

After the first evaluation, on the request of the ERNs and the Board of Member States, the European Commission set up a Working Group with the objective of recommending improvements to the evaluation methodology and process, to be applied to the next evaluation cycle (expected to be carried out in 2027).

Part 2: The 24 European Reference Networks

The 24 European Reference Networks in figures

Table 1: ERNs members, as of December 2025 (distributed by ERN Centre type)

ERN	Full Members	Associated National Centres	National Coordination Hubs	TOTAL
BOND	43	2	4	**49**
CRANIO	35	5	2	**42**
Endo-ERN	92	11	1	**104**
EpiCARE	38	10	2	**50**
ERKNet	64	7	2	**73**
ERN-EYE	51	5	3	**59**
ERNICA	39	9	4	**52**
ERN-LUNG	78	7	2	**87**
ERN-RND	63	2	2	**67**
ERN-SKIN	52	2	2	**56**
EURACAN	90	7	2	**99**
EuroBloodNet	89	4	3	**96**
eUROGEN	51	1	4	**56**
EURO-NMD	73	5	2	**80**
GENTURIS	44	5	2	**51**
GUARD-HEART	44	7	2	**53**
ITHACA	65	2	3	**70**
MetabERN	85	4	2	**91**
PaedCAN	79	9	2	**90**
RARE-LIVER	52	7	3	**62**
ReCONNET	54	6	3	**63**
RITA	61	7	2	**70**
TRANSPLANTCHILD	33	4	3	**40**
VASCERN	40	4	2	**46**
TOTAL	**1 415**	**132**	**59**	**1 606**

ERN on rare bone diseases (ERN BOND)

Rare bone diseases encompass disorders of bone formation, modelling, remodelling and removal, and defects of the regulatory pathways of these processes. They result in short stature, bone deformity, teeth anomalies, pain, fractures and disability, and can adversely influence neuromuscular function and haemopoiesis.

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ERN BOND (https://ernbond.eu/) brings together all rare bone diseases - congenital, chronic and of genetic origin - which affect cartilage, bones and dentin. The network initially focused on osteogenesis imperfecta (OI), X-linked hypophosphataemic rickets (XLH) and achondroplasia (ACH) as exemplars, based on disease prevalence, diagnostic and management difficulty, and novel emergent therapies. More recently, as systematic approaches were established, ERN BOND has been moving on to rarer bone diseases.

NETWORK COORDINATOR

Dr Luca Sangiorgi
Rizzoli Orthopaedic Institute, Bologna, Italy

Working with patients, ERN BOND aims to develop patient journeys, as well as guidelines for the development and dissemination of best practice. As new therapeutics are developed, the network aims to ensure rapid access to studies for affected patients.

ERN BOND enables skill development through eHealth and telemedicine platforms, alongside working visits, training courses and dissemination activities. The network aims to reduce diagnosis time through fewer inappropriate tests, more accurate diagnosis and new viable treatments.

ERN on rare craniofacial anomalies and ear, nose and throat (ENT) disorders (ERN CRANIO)

ERN CRANIO focuses on rare and complex craniofacial anomalies, and ear, nose and throat (ENT) disorders. These conditions cover malformations of the brain, skull and face, including specific disorders such as Craniosynostosis and Craniofacial Microsomia, cleft lip and cleft palate, orodental abnormalities, congenital deafness and anatomical airway disorders.

ERN CRANIO (https://www.ern-cranio.eu/) incorporates the expertise of patients, their representatives, nurse specialists and all care providers such as surgeons, psychologists, radiologists, anaesthesiologists and geneticists.

ERN CRANIO aims to pool disease-specific expertise, knowledge and resources from across the EU/EAA to achieve health goals that may otherwise be unachievable in a single country. These health goals include further developing clinical skills, increasing patient access to high-quality expert care, and making improved diagnosis-specific information available to healthcare professionals, patients, and their families and carers.

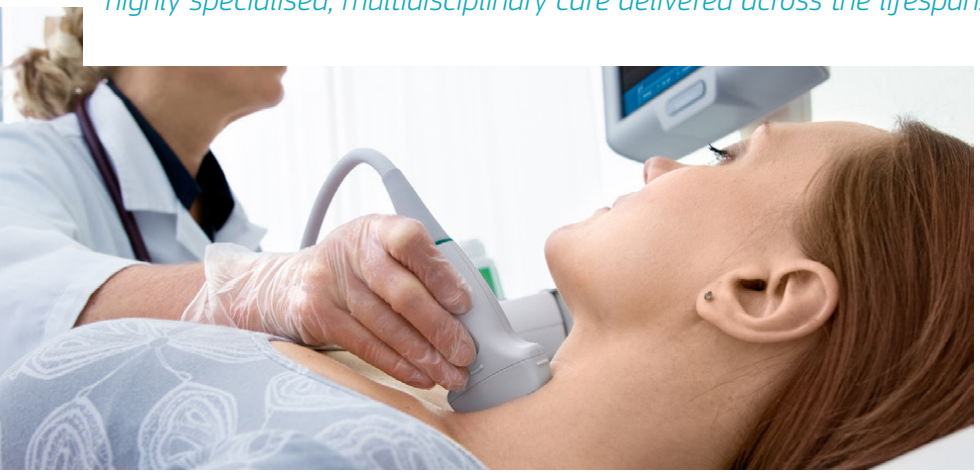
In doing so, ERN CRANIO also seeks to reduce health inequalities by standardising practices and making high-quality care, information and resources accessible to healthcare providers, patients, and their families and carers across Europe.

NETWORK COORDINATOR

Professor Dr Irene Mathijssen
Erasmus University Medical Center, Rotterdam, The Netherlands

ERN on rare endocrine conditions (Endo-ERN)

Rare endocrine conditions include too much, too little, or inappropriate hormonal activity, hormone resistance, tumour growth in endocrine organs, and diseases with consequences for the endocrine system. Prevalence varies widely, spanning ultra-rare, rare, and low-prevalence conditions. Patients may require highly specialised, multidisciplinary care delivered across the lifespan.



Endo-ERN (https://endo-ern.eu/) is organised into eight main thematic groups covering the full spectrum of congenital and acquired endocrine conditions. These thematic groups are: adrenal disorders; disorders of calcium and phosphate homeostasis; genetic disorders of glucose and insulin homeostasis; genetic endocrine tumour syndromes; disorders of growth and genetic obesity syndromes; hypothalamic and pituitary conditions; conditions affecting sex development and maturation; and thyroid disorders.

The lifespan care requirement means that adult and paediatric endocrinologists work collaboratively on all aspects of network activity including guideline development. This close partnership is a unique feature of Endo-ERN and reflects its strong focus on transition of care, ensuring continuity for patients as they move from childhood to adulthood.

Network members contribute to a wide range of activities, including cross-border virtual consultations for complex cases (CPMS 2.0), giving patients across Europe access to specialist expertise without the need to travel and supporting equality of care. They also actively contribute to the European Registries for Rare Endocrine and Bone Conditions (EuRREB), strengthening data collection and collaborative research to improve patient care.

The European Society of Endocrinology (ESE) and the European Society for Paediatric Endocrinology (ESPE) partner with Endo-ERN to promote rare endocrine conditions and enhance shared education and expertise across the endocrinology community.

Endo-ERN works to make it easier for people with rare endocrine conditions to get the right diagnosis, the right treatment, and high-quality care. The network connects experts across Europe and supports joint work on care, research, and training, always taking patients' views into account.

NETWORK COORDINATOR

Professor Alberto M. Pereira
Amsterdam University Medical Centre, Amsterdam, The Netherlands

ERN on rare and complex epilepsies (EpiCARE)

Epilepsy affects at least six million people in Europe. Epilepsies can originate from many different neurological aetiologies. Treatment choices, outcomes and the overall prognosis depend on which aetiologies are at work, and a prompt diagnosis. When appropriately chosen and prescribed, traditional anti-seizure medications help nearly 70% of those affected to reduce the frequency of the epileptic seizures or to achieve seizure freedom. Epilepsy-surgery, following a meticulous pre-surgical evaluation, can help cure several focal epilepsies. Rare and complex epilepsies require multi-disciplinary management from the onset.

ERN EpiCARE (https://epi-care.eu/) works to help patients to be diagnosed earlier, to facilitate equitable access to specialised care. The network members offer full access to early pre-surgical evaluation and epilepsy surgery, share their expertise with other medical teams, and foster research on innovative diagnostic tools and causal treatments. Supported by the European Consortium for Epilepsy Trials (ECET), EpiCARE contributes to further develop innovative clinical trials for new treatments.

Several times a month, the network organises patient case discussion multidisciplinary sessions with the participation of EU experts. It actively contributes to EU-funded initiatives such as SOLVE-RD; ERICA; REALISED; ERDERA. Collaborative projects are systematically promoted and supported. Its members are also active participants in transversal working groups on neurological disorders, particularly those involving ERN-RND, ERN-NMD, MetabERN and ITHACA.

ERN EpiCARE has launched, in collaboration with all related scientific societies, numerous activities to generate and build knowledge, including interactive educational webinars and updates on clinical practice guidelines and recommendations. A fully structured educational programme is in place, aiming to support early- and mid-career experts to present their scientific works and to steadily enrich their knowledge in the vast field of epilepsy care and research.

To increase awareness of best practices and care pathways, ERN EpiCARE collaborates with several patient associations, most of them also represented in the EpiCARE Patient Advocacy Group. Expert clinicians and patient advocates closely work together to identify patient needs, enrich the design of clinical trials, define research priorities, and to produce disease-specific leaflets including validated information for families and non-expert caregivers. All the above activities are made possible with the support from a dedicated Project Managers team, funded by the European Commission.

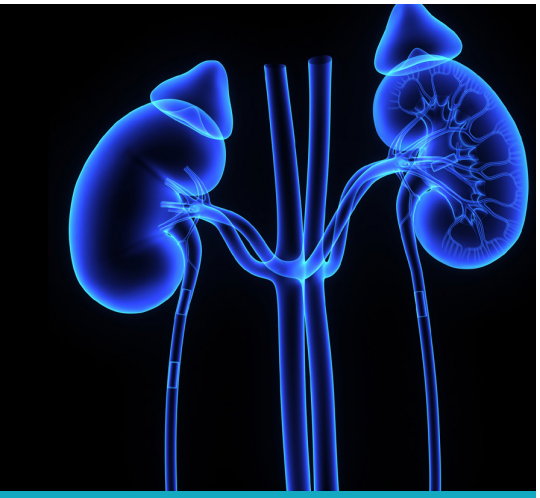
NETWORK COORDINATOR

Professor Alexis Arzimanoglou
Hospital Infantil Sant Joan de Déu (HSJD), Barcelona, Spain

ERN on Rare Kidney Diseases (ERKNet)

Rare and complex kidney diseases, which affect an estimated 2 million Europeans, include a broad range of congenital, inherited and acquired conditions.

State-of-the-art diagnostic tools can provide valuable information on disease prognosis and therapeutic options. However, access to testing is not universal. Due to delayed diagnosis and inadequate treatment, many rare kidney diseases unnecessarily progress to kidney failure.



NETWORK COORDINATOR

Professor Franz Schaefer
Universitätsklinikum Heidelberg, Germany

ERKNet (https://www.erknet.org/) unites Europe´s leading centres for rare kidney disease with the shared goal of improving diagnosis, treatment and long-term outcomes of all affected patients.

ERKNet aims to enhance the management of rare kidney diseases by promoting coordinated and consistent care across Europe. Its virtual consultation service offers clinicians facing new or complex cases direct access to expert advice. Furthermore, ERKNet facilitates harmonised, high-quality care by developing evidence-based clinical guidance documents and supporting their implementation in practice.

Since awareness and knowledge among healthcare professionals are essential for identifying and treating rare kidney diseases, ERKNet has introduced a three-year postgraduate curriculum. Combining clinical training, webinars, and e-Learning, this programme delivers comprehensive education on the entire spectrum of rare kidney diseases. Graduates are recognised as 'European Rare Kidney Disease Specialists'.

Research is strongly integrated into the network's mission. Collaborative research projects and exchange programmes bring together scientists from many countries to explore disease mechanisms, evaluate new therapies and document long-term outcomes. These efforts are supported by ERKReg, the European Rare Kidney Disease Registry, which collects real-world patient data and hosts dedicated sub registries for defined disease groups. This resource underpins epidemiological studies, cohort identification and benchmarking of clinical performance across the specialist centres, supporting harmonised and optimised care for rare kidney disorders in all ERKNet hospitals and clinics.

ERKNet works closely with other European reference networks, the European renal societies, patient groups and scientific partners. These partnerships strengthen advocacy, expand educational reach, and create joint research opportunities, maximising the network´s impact on the rare kidney disease community.

ERN on rare neurological diseases (ERN-RND)

ERN-RND creates and shares knowledge and coordinates care for patients affected by rare neurological diseases involving the most common central nervous system pathological conditions. It covers cerebellar ataxias and hereditary spastic paraplegias; Huntington's disease and other choreas; frontotemporal dementia; dystonia, (non-epileptic) paroxysmal disorders and neurodegeneration with brain iron accumulation; leukoencephalopathies, and atypical parkinsonian syndromes.

ERN-RND (https://www.ern-rnd.eu/) unites expert centres and affiliated partners in 24 European countries, as well as patient representatives. It focuses on highly specialised healthcare services such as next generation sequencing diagnostics, deep brain stimulation and advanced therapies, and generates and disseminates both overarching and disease group-specific knowledge.

ERN-RND follows a systematic three-step approach to improve care quality for RND patients:

1. Mapping and analysis of care inequalities on EU level,

2. Development of healthcare interventions using the ERN toolbox composed of:

   - The CPMS 2.0: ERN-RND has successfully set-up care pathway specific multidisciplinary team discussions including treatment eligibility panels for specific diseases.
   - The ERN-RND registry, which is fully functional and collects the ERDRI dataset for all patients seen in ERN-RND.
   - The postgraduate curriculum established by ERN RND for RND based on the UEMS approved European Training Requirement for RND, utilising created training measures (webinars, e-learnings, stays at expert centres).
   - Several guidelines under development in the disease expert groups
   - Other specific clinical decision support tools (including diagnostic flowcharts, disease scales and therapeutic algorithms) have been developed and are regularly updated.
   - Patient journeys which are in development and led by the patient representatives. Respective information leaflets are available in many European languages and have been actively disseminated.

3. Measurement of effect and – if necessary – adaption of the interventions.

ERN-RND cooperates with the European Academy of Neurology (EAN); the European Paediatric Neurology Society (EPNS); the European section of the International Parkinson and Movement Disorder Society (MDS); the European Federation of Neurological Associations (EFNA); and the European Academy of Childhood Disability (EACD). With the other two 'Neuro-ERNs' - EURO-NMD and EpiCARE – ERN-RND has established cross-ERN working groups.

NETWORK COORDINATOR

Dr Holm Graessner
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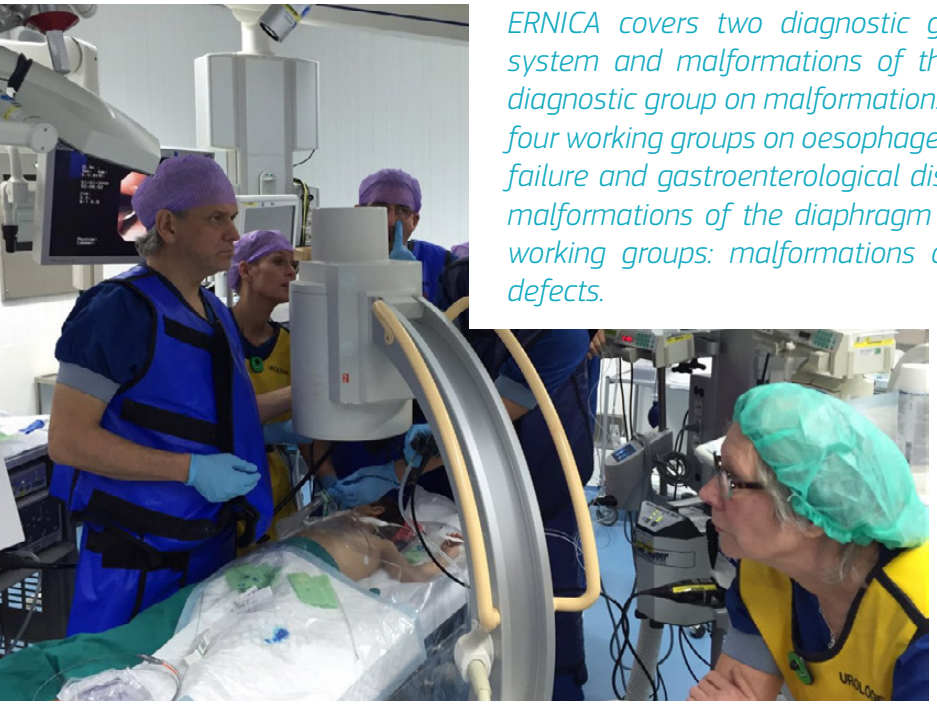
ERN on rare inherited and congenital (digestive and gastrointestinal) anomalies (ERNICA)



ERNICA covers two diagnostic groups: malformations of the digestive system and malformations of the diaphragm and abdominal wall. The diagnostic group on malformations of the digestive system work comprises four working groups on oesophageal diseases, intestinal diseases, intestinal failure and gastroenterological diseases. The diagnostic group working on malformations of the diaphragm and abdominal wall is made up of two working groups: malformations of the diaphragm, and abdominal wall defects.

ERNICA (https://www.ern-ernica.eu/) aims to pool disease-specific expertise, knowledge and resources from across the EU/EAA, to achieve health goals that may otherwise be unachievable in a single country. These health goals include development of clinical skills; increased patient access to high-quality expert care; and increased diagnosis-specific information available to health-care professionals, patients and their families and carers.

NETWORK COORDINATOR

Professor Dr René Wijnen
Erasmus University Medical Center, Rotterdam, The Netherlands

Working groups are co-led by ERNICA healthcare professionals and patient representatives. Nine areas of work are applicable to all diagnostic groups - management, dissemination, evaluation, standards of care, training, research, eHealth, foetal medicine; and networking.

In doing so, ERNICA also seeks to reduce health inequalities across Europe by standardising practices and making high-quality care, information and resources accessible to healthcare providers, patients and their families and carers across Europe.

ERN on rare respiratory diseases (ERN-LUNG)

Rare and complex lung diseases require multidisciplinary care and psycho-social support. Their complexity can be due to the underlying genetic mechanism of the disease, or the secondary changes and damage done to other organ systems. Early diagnosis and access to specialist care improve outcomes for many of these conditions.

ERN LUNG (https://ern-lung.eu/) addresses all rare and complex diseases of the respiratory system, including Interstitial lung diseases (ILD), Cystic fibrosis (CF), Bronchiectasis (BE), Pulmonary hypertension (PH), Primary ciliary dyskinesia (PCD), Sarcoidosis (SARC), Alpha-1 antitrypsin deficiency (AATD), Mesothelioma (MSTO), Chronic lung allograft dysfunction (CLAD), and Other rare lung diseases (ORLD).

The network aims to improve expertise across Europe to advance standards of care, quality of life, and prognosis for the entire spectrum of rare pulmonary diseases. Members of ERN-LUNG develop and disseminate guidelines, promote common treatment approaches, enhance cross-border access to diagnosis and treatment, and assemble sufficiently large cohorts for clinical studies, clinical trial networks, drug development, and natural history studies.

Two registries have been built up in the past years: ERN-LUNG PRIME, with input from our Healthcare providers, and BREATHeREGISTRY, which is a patient-driven registry. Furthermore, the ERN-LUNG Academy has been training since 2023 a significant number of medical professionals who wish to get proof of knowledge on rare respiratory diseases, through Webinars and a practical stay in one of the network's expert centres.

ERN-LUNG provides patients with access to interdisciplinary teams, providing online second opinions on complex cases without requiring patients to travel. This is achieved through an online expert advice system, by online case panel discussions, and – if needed – by cross-border referral. Furthermore, the Undiagnosed patient's pathway has depicted a standard operating procedure, defining essential steps and criteria from the first contact to the healthcare system in primary care towards specialist centres and national reference networks, before the undiagnosed patient gets referred to ERN-LUNG.

NETWORK COORDINATOR

Professor Thomas O.F. Wagner
Universitätsklinikum Frankfurt, Germany

ERN on rare, complex, and undiagnosed skin disorders (ERN-Skin)

Many skin conditions have a severe impact on patients and can be associated with a risk of cancer. Diagnosis of rare and complex skin diseases consists of a full assessment of the skin and mucous membrane, as well as other systems, in addition to skin biopsies. Only experienced dermatologists can differentiate between these complex conditions, and the absence of an expert diagnosis is a barrier to treatment. This can be a profound physical and psychological burden for patients.

NETWORK COORDINATOR

Professor Christine Bodemer
Assistance Publique-Hôpitaux de Paris, Hôpital Necker-Enfants Malades, France

ERN Skin (https://ern-skin.eu/) brings together leading experts in the field of rare child and adult skin diseases to exchange knowledge, update and develop best practice guidelines, improve professional training and patient education, and set up research programmes.

It aims to improve healthcare organisation with the pooling of resources, including a platform with expert collaborative discussions on difficult cases. For every disease covered, core multidisciplinary teams include at minimum a dermatologist, a nurse, a psychologist, a geneticist, a dietician and a pathologist, along with other specialists as required.

ERN Skin also develops rare skin disease registries, allowing participation in research programmes and clinical trials with well-characterised patients, as well as the stimulation of therapeutic research with sufficiently large cohorts of patients. In addition, a comprehensive socio-economic study on the individual burden of diseases will be conducted.

ERN on rare adult solid cancers (ERN EURACAN)

The Surveillance of Rare Cancers in Europe (RARECARE) defines rare cancers as malignant disorders with an incidence of fewer than six per 100,000 per year. They account for around 20-25 percent of all new cancer diagnoses and 30 percent of cancer deaths.

Experts agree that patients with rare cancers should, from initial diagnosis, be referred to certified reference centres to benefit from the most up-to-date, multidisciplinary expertise - from effective therapies to evidence-based treatment guidelines – and which can ensure appropriate care for all patients, regardless of the initial point of access.

ERN EURACAN (https://www.euracan.eu/) covers more than 300 rare adult solid cancer types, grouping them into ten domains corresponding to the RARECARE classification and the International Classification of disease (ICD10). The network collaborates closely with patient representatives from European Patient Advocacy Groups (ePAGs) to provide information and perspectives on patients' needs and expectations.

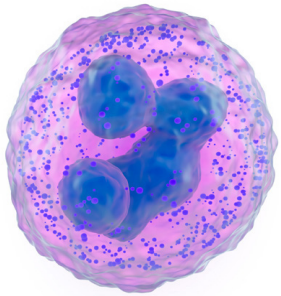
Since its inception, EURACAN has reached 25 EU and EAA countries, aiming to standardise patient management and improve survival rates by generating and sharing best practice tools, and regularly updating diagnostic and therapeutic clinical practice guidelines in collaboration with several scientific societies. The network has also developed multilingual communication tools for both patients and physicians. In addition, EURACAN's work on establishing registry models for adult rare tumours marks a significant advance in strengthening data collection, harmonisation, and patient care across Europe.

EURACAN builds on well-established European networks and successful clinical trials, like the European Organisation for Research and Treatment of Cancer (EORTC) and the European Society for Medical Oncology (ESMO), drawing on their experience, data, and expertise to advance care for rare cancer patients. This foundation allows the network to strengthen clinical practice, support new research, and improve access to specialised care across Europe.

NETWORK COORDINATOR

Professor Dr. Jean-Yves Blay
Centre Léon Bérard, Lyon, France

ERN on rare haematological diseases (ERN-EuroBloodNet)



Rare haematological diseases (RHDs) comprise disorders affecting blood and bone marrow cells, lymphoid organs, and coagulation factors. ERN-EuroBloodNet covers more than 450 RHDs according to ORPHANET classification, which fall into 6 groups: Myeloid malignancies, Lymphoid malignancies, Rare red blood cell defects, Bone marrow failure syndromes, Rare coagulation disorders and Haemochromatosis and other inherited disorders of iron metabolism.

Accurate diagnosis of RHDs requires significant clinical expertise and access to a wide range of specialised laboratory tests and imaging technologies. These resources enable precise classification according to WHO criteria, using recognised international scoring systems and biomarkers whenever possible. However, because many RHDs are extremely rare, and symptoms may be nonspecific, diagnosis is often delayed or missed, particularly in older patients.

NETWORK COORDINATOR

Professor Pierre Fenaux
Assistance Publique-Hôpitaux de Paris (AP-HP), Hôpital Saint-Louis, Paris, France

Treatment poses additional challenges. Many therapies require highly specialised infrastructures, multidisciplinary teams, or limited-availability interventions such as allogeneic stem cell transplantation or specific coagulation factors. While some Member States have established preventive programmes for selected conditions, there remains a clear need for greater harmonisation in screening and early detection across Europe.

Throughout its seven years of activity, ERN-EuroBloodNet (https://eurobloodnet.eu/), working closely with the European Haematology Association (EHA), has implemented a broad range of transversal and disease-specific initiatives with the goal of improving care for patients with RHDs. Key achievements include developing and disseminating clinical practice guidelines and clinical decision-making tools for clinicians and patients, scaling up knowledge and strengthening training with educational programs directed to clinicians as well as to patients.

The network is also successfully mapping resources at EU-level, coordinating expert repositories, and facilitating patient referral across borders, as well as increasing opportunities for clinical research and clinical trials within the field, reducing data fragmentation and improving EU-wide epidemiological insight through ENROL, the ERN's patient registry.

Patient involvement has been central to ERN-EuroBloodNet's mission. The active participation of European Patient Advocacy Groups (ePAGs) and patient associations ensures that initiatives promote patient empowerment, therapeutic education, and effective advocacy, reflecting the Network's strong commitment to a truly patient-centred approach.

ERN on rare uro-recto-genital diseases and complex conditions (ERN eUROGEN)

ERN eUROGEN addresses rare uro-recto-genital diseases and complex conditions across the life course, covering congenital anomalies in childhood, adult functional and reconstructive conditions, and rare urogenital tumours. These conditions require multidisciplinary expertise, coordinated pathways, specialised surgery, post-operative care, and long-term follow-up supported by expert teams across Europe.

ERN eUROGEN (https://eurogen-ern.eu/) strengthens collaboration through coordinated governance, clear communication, and shared priorities. It works with its specialised member centres and Supporting Partners (expert professional societies, individual specialists, and patient organisations) who contribute expertise, extend outreach, and support training, dissemination, and best-practice exchange. ERN eUROGEN also collaborates with other ERNs on cross-cutting rare disease issues.

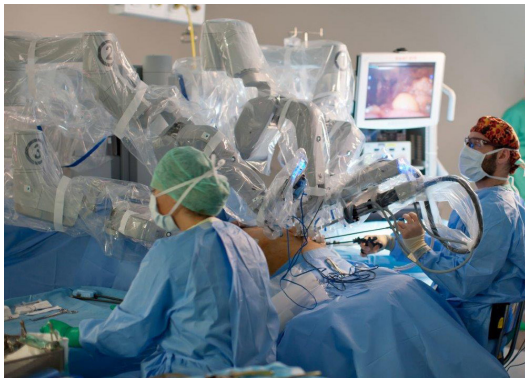
The network disseminates accessible, high-quality information for clinicians, patients, and the public to raise awareness and promote the use of ERN tools and resources.

Progress is monitored through structured evaluation using activity data, indicators, and stakeholder feedback to assess performance and guide improvement.

Cross-border clinical collaboration is enabled through the Clinical Patient Management System (CPMS 2.0), allowing expert virtual consultations and improving diagnosis, treatment planning, and continuity of care, including paediatric-to-adult transition.

A significant development is the ERN eUROGEN registry, designed to collect long-term outcomes over 15–20 years. This strengthens the evidence base, allows comparison of care across centres, and supports research and innovation.

Training and education programmes - including webinars, courses, and books - support new specialists and continuous learning. The network also develops and updates Clinical Practice Guidelines, Clinical Decision Support Tools, and patient information to harmonise best practice across Europe.



ERN eUROGEN undertakes capacity-building, best-practice sharing, and dedicated activities for Ukraine in collaboration with Ukrainian healthcare authorities.

Through its “Share. Care. Cure.” ethos, ERN eUROGEN advances diagnostics, treatment, and long-term outcomes for people living with rare uro-recto-genital diseases across Europe.

NETWORK COORDINATOR

Peter Mulders
Radboud University Medical Center, The Netherlands

ERN on neuromuscular diseases (ERN EURO-NMD)

Neuromuscular diseases (NMDs) occur from birth to late adulthood and are characterised by muscle weakness and wasting. They may also be associated with other symptoms including fatigue, pain, numbness, blindness, swallowing difficulties, breathing difficulties and heart disease. Most NMDs are progressive and debilitating, with reduced lifespan and quality of life.

NETWORK COORDINATOR

Dr. Teresinha Evangelista
Sorbonne Université - Pitié Salpêtrière Hospital - Assistance Public Hôpitaux de Paris, France

There are significant gaps and disparities in access to diagnostics and treatment across Europe. Major challenges in improving outcomes include the delay in referral from primary care to a specialist centre and managing the transition from paediatric to adult services.

ERN EURO-NMD (https://ern-euro-nmd.eu/) unites Europe's leading experts to provide patients with access to specialist care through virtual and in-person consultations. The network works to shorten time to diagnosis, improve diagnostic yield and increase access to appropriate care pathways.

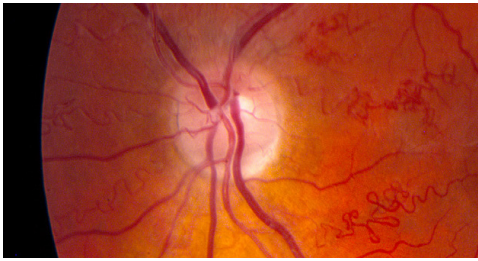
In the first half of 2021, a total of 12,882 new patients consulted EURO-NMD experts, and EURO-NMD partners participated in 258 clinical trials. Since 2018, the number of new patients consulted by network centres has increased by 37.5 percent and the participation of EURO-NMD partners in clinical trials has grown by 63 percent.

In addition, the network continuously develops new guidelines and provides healthcare professionals and patients with disease-specific best practice information. The knowledge generated and curated by the network is widely available online and through publicly available webinars, as well as via eHealth tools such as discussions carried out using the Clinical Patient Management System (CPMS 2.0). A Moodle-based learning management system (LMS) has been developed, and the courses are being finalised. Once available, successful participants will be able to gain certification.

Building on a strong legacy of European cooperation, the network continues to foster collaborations with the potential to drive research and therapy development to address unmet patient needs. Promoting transnational data sharing through ethically robust, high-quality registries and research data platforms is also a key priority.

ERN on rare eye diseases (ERN-EYE)

Rare Eye Diseases (REDs) are the leading cause of visual impairment and blindness among children and young adults in Europe. More than 900 REDs are listed in the Orphanet portal for rare diseases and orphan drugs, ranging from more prevalent diseases such as retinitis pigmentosa - which has an estimated prevalence of 1 in 5,000 – to extremely rare conditions described only once or twice in medical literature.



In close collaboration with European Patient Advocacy Groups (ePAGs), ERN-EYE (https://www.ern-eye.eu/) addresses these diseases in four thematic groups:

- rare diseases of the retina
- neuro-ophthalmology rare diseases
- paediatric ophthalmology rare diseases
- and rare anterior segment conditions.

In addition, six transversal working groups are addressing issues common to the four main themes, respectively on Low Vision, Daily Life and Patients Groups; Genetic Diagnostics; Registries and Epidemiology; Research; National Integration; Clinical Patients Management Systems (CPMS 2.0) and Digital Medicine.

One of the most important ERN tools is the CPMS, a virtual clinic IT platform. Through CPMS, ERN-EYE provides advice both within and beyond the network. It also organises multidisciplinary Ground Rounds called GREET and advises on challenging genomic variants interpretation through RED-VAR meetings.

ERN-EYE aims to improve patients' diagnosis and care across the EU by:

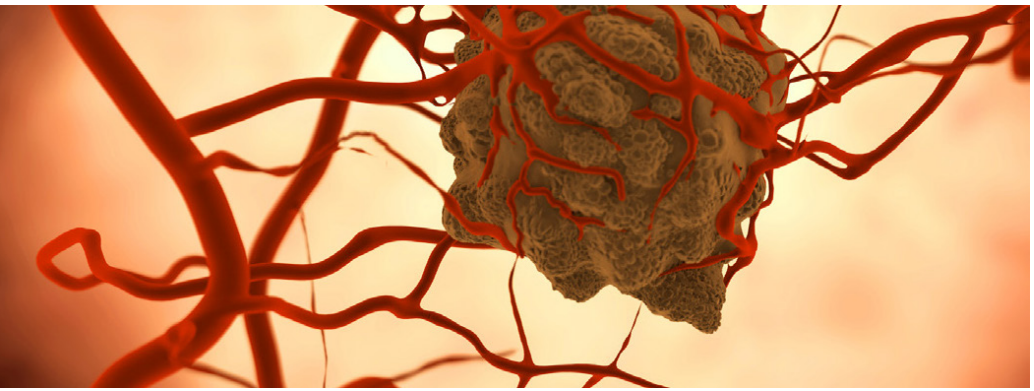
- strengthening expert networking and facilitating knowledge and information exchange
- developing educational and training programmes (such as webinars or e-Learning programmes – including one on Inherited Retinal Diseases and another recently launched one on Paediatric REDs)
- creating a European comprehensive and interoperable registry (REDgistry), designed to collect essential data from patients with REDs, operational since October 2025
- developing guidelines and good practices documents
- and by contributing actively to international multidisciplinary research projects, such as the SeeMyLife research project, which assesses the quality of life of children with visual impairment caused by REDs.

NETWORK COORDINATOR

Professor Hélène Dollfus
Hôpitaux Universitaires de Strasbourg, France

ERN on genetic tumour risk syndromes (ERN GENTURIS)

Genetic tumour risk syndromes are disorders in which inherited genetic variants strongly predispose individuals to the development of tumours. The lifetime risk of cancer can be as high as 100 percent. While there is considerable diversity in the organ systems that may be affected, individuals affected by these conditions share similar challenges: delay in diagnosis, lack of prevention for patients and healthy relatives, and therapeutic mismanagement. At present, few people with genetic tumour risk syndromes are accurately diagnosed with the disorders.



NETWORK COORDINATOR

Prof. dr Marjolijn Ligtenberg
Radboud University Medical Center
Nijmegen, The Netherlands

ERN GENTURIS (https://www.genturis.eu/l=eng/home.html) is working to improve identification of these syndromes and to minimise variation in clinical outcomes, design and implement EU-guidelines, care pathways and patient journeys. This ERN also works to develop the GENTURIS registry, support research, and empower patients. The network educates both the public and healthcare professionals via its website, and by organising regular webinars and courses, and fostering sharing of best practice across Europe. Through virtual, cross-border multidisciplinary team meetings, ERN GENTURIS improves the care of complex cases by facilitating discussions and collaborative decision-making. The network is also working to improve the access to and the quality and the interpretation of genetic testing and is increasing patient participation in clinical research programmes.

ERN GENTURIS cooperates with other ERNs to improve the care of patients with genetic tumour risk syndromes who may develop conditions that fall under the expertise of other networks, ensuring comprehensive, cross-specialty support.

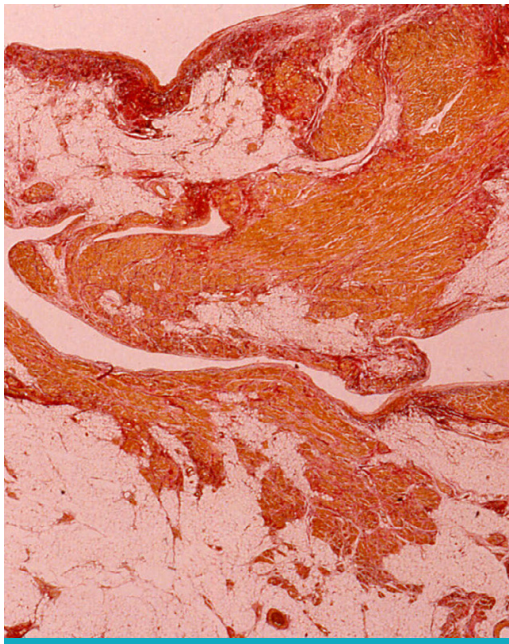
ERN on uncommon and rare diseases of the heart (ERN GUARD-Heart)

Rare cardiac diseases can present throughout a person's life, and most of them are usually either genetic (inheritable) disorders or those which develop during embryogenesis (congenital heart defects). These conditions are characterised by a wide range of symptoms and signs which vary not only from disease to disease, but also from patient to patient. Most of these cardiac diseases carry a unique susceptibility to sudden death at a young age and may occur in otherwise healthy people.

ERN GUARD-Heart (https://guardheart.ern-net.eu/) has identified five thematic areas: familial electrical diseases in adults and children; familial cardiomyopathies in adults and children; special electrophysiological conditions in children; congenital heart defects; and other rare cardiac diseases. These themes align with those designated by the International Classification of Diseases (ICD10) and Orphanet and are subject to the clinical guidelines of the European Society of Cardiology (ESC).

The network seeks to strengthen the coordination of expertise and resources to facilitate the pooling of multidisciplinary knowledge, which is then mapped and disseminated to the public.

Healthcare services are provided through a shared eHealth platform, which ensures patients get wider access to expertise and healthcare professionals around Europe. By fostering closer cooperation between experts, new scientific knowledge is acquired and shared to support the development of new diagnostic and therapeutic procedures, and to identify new rare cardiac diseases.



NETWORK COORDINATOR

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ERN on rare malformation syndromes, intellectual and other neurodevelopmental disorders (ERN-ITHACA)

ERN ITHACA (Intellectual disability, TeleHealth, Autism and Congenital Anomalies) echoes the diagnostic 'odyssey' experienced by so many patients with developmental anomalies. The network brings together more than 70 clinical genetics department across EU academic hospitals, including experts in rare neurodevelopmental disorders (NDDs) – mainly intellectual disability (ID) and autism spectrum disorder (ASD) - as well as rare multiple congenital anomalies.

NETWORK COORDINATOR

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Université de Paris & Assistance Publique-Hôpitaux de Paris, Hôpital Universitaire Robert-Debré, Paris, France

ERN ITHACA (https://ern-ithaca.eu/) covers the clinical and biological/genetic diagnosis of these developmental anomalies, the coordination of multidisciplinary care and treatment, and prenatal diagnosis and foetal pathology.

Rare developmental anomalies affect many children and adults - for example, approximately two percent of newborns will be affected by ID and at least one percent by ASD (with or without ID). Roughly half of patients with ID, and more than one in ten with ASD, have a monogenic or a chromosomal disorder. Congenital malformations affect one in 40 babies, often as part of complex syndromes which also display NDDs. More than 5,000 rare syndromes have been described.

ERN ITHACA unites medical experts and ePAG representatives, providing collaborative support for clinical research, developing best practice consensus and guidelines, and improving the early diagnosis, care and cure of patients. The network has also established the International Library of Intellectual Disability and Anomalies of Development (ILIAD) patient registry.

The network develops telemedicine and tele-expertise to facilitate collegial discussions between referring doctors and researchers across the EU and produces training and e-learning tools for health professionals, lay persons and ePAGs.

ERN on hereditary metabolic disorders (MetabERN)

Rare inherited metabolic diseases (IMDs), of which there are more than 1400, are individually rare but collectively frequent. Many metabolic diseases have severe - sometimes life-threatening - implications for patients. These conditions include disorders of all organs, can affect people of any age, and require multidisciplinary collaboration between a range of professionals.

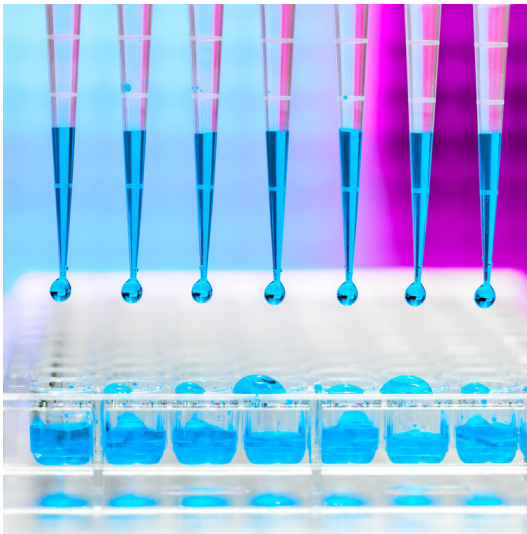
Early diagnosis can improve outcomes, but only five percent of known IMDs are currently included in newborn screening programmes in Europe and there is a need for national programmes to be harmonised. Many IMDs lack knowledge about their natural history and the efficacy and safety of therapies, while long-term follow-up is incomplete.

MetabERN (https://metab.ern-net.eu/) seeks to improve the lives of people affected by this highly heterogenous group of diseases by dividing them into seven main categories. The network represents the most comprehensive, pan-metabolic, pan-European, patient-centred network, aiming to transform how care is provided to patients with IMDs in Europe.

MetabERN strives to pool knowledge and improve information exchange to enhance diagnosis and care in areas lacking expertise.

The network supports Member States to provide highly specialised care to patients and to advance innovation in medical science and health technologies for IMDs. It also provides cross-border medical training and research on IMDs and supports all patient initiatives towards harmonising and improving all aspects of the care chain.

With its fully operational unified European registry for IMDs (U-IMD), MetabERN effectively generates patient data for research purposes. This allows a detailed assessment of the natural history of IMDs, as well as the investigation of further research questions, including prospective analysis of preventive and therapeutic interventions in patients with IMDs. Moreover, U-IMD is the first observational, non-interventional patient registry to encompass all 1400+ IMDs.



NETWORK COORDINATOR

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ERN on paediatric cancer (haemato-oncology) (ERN PaedCan)

Paediatric cancer is rare and comes in multiple subtypes. Each year across Europe, 35,000 children and young people are diagnosed with cancer and 6,000 paediatric cancer patients die - the leading fatal disease for children aged over one. More than half a million long-term survivors of childhood cancer are alive today in Europe, with two-thirds of them experiencing long-term health and psycho-social problems due to their disease.

NETWORK COORDINATOR

Professor Dr. Ruth Ladenstein
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Average survival rates have improved in recent decades - progress for some conditions has been dramatic, while for others the outcomes remain very poor. Significant survival inequalities are a challenge, with worse outcomes in Eastern Europe.

ERN PaedCan (https://paedcan.ern-net.eu/) works to improve access to high-quality healthcare for children and adolescents with cancer whose conditions require specialist expertise and tools not widely available due to low case volumes and lack of resources. It builds on previous EU-funded projects ENCCA, PanCare and ExPO-r-Net.

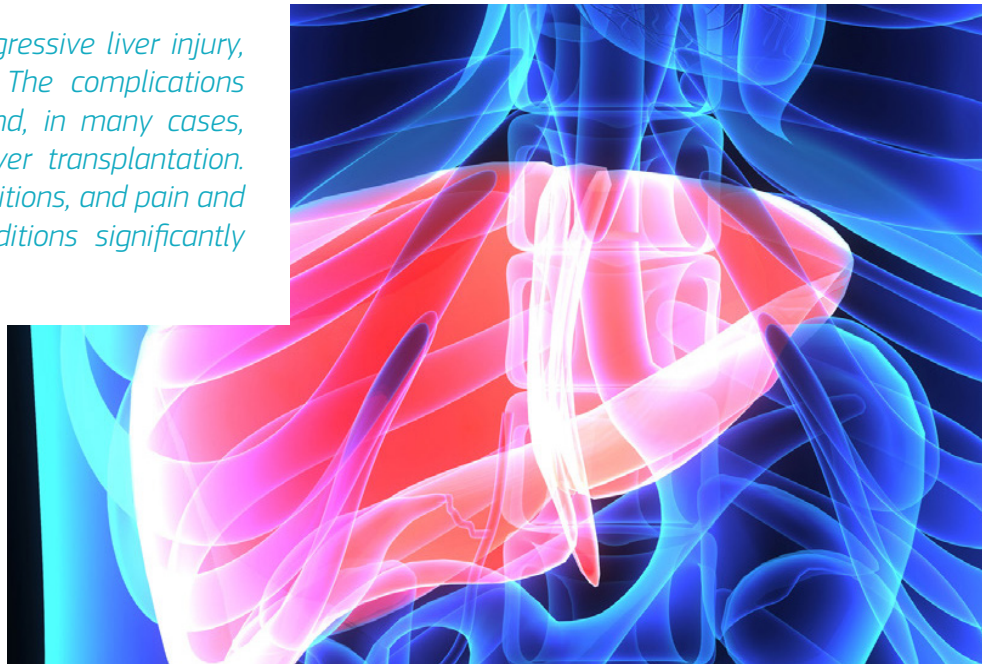
Members include a strong interactive network of paediatric hospitals and units specialised in paediatric and adolescent cancer care. Together with the European Society for Paediatric Oncology (SIOPE), European Standard Clinical Practice (ESCP) guidance protocols have been established as a common reference for upfront treatments in all major paediatric cancer care settings, and a virtual paediatric oncology tumour board uses eHealth tools to share expertise and advice. Education and training are fostered through webinars, meetings and exchange programmes.

ERN PaedCan strives to achieve equity in childhood cancer outcomes across Europe and to help implement SIOPE's Strategic Plan, strongly supported by the Horizon Europe Cancer Mission, Europe's Beating Cancer Plan and the Pharmaceutical Strategy for Europe.

The network aims to increase childhood cancer survival and quality of life by fostering cooperation, research and training, with the ultimate goal of reducing current inequalities in childhood cancer survival and healthcare capabilities in EU Member States.

ERN on rare hepatological diseases (ERN RARE-LIVER)

Rare liver diseases can cause progressive liver injury, leading to fibrosis and cirrhosis. The complications of cirrhosis can lead to death, and, in many cases, the only effective treatment is liver transplantation. Fatigue, pruritus in cholestatic conditions, and pain and abdominal swelling in cystic conditions significantly affect patients' quality of life.



In paediatric patients, delays in diagnosis, failure to thrive and attain developmental milestones, and the challenge of transition in care through adolescence are additional complicating factors.

ERN RARE-LIVER (https://rare-liver.eu/) addresses three disease themes: autoimmune liver disease; metabolic, biliary atresia and related liver disease; and structural liver disease. For the first time in liver disease, the network fully integrates adult and paediatric care with a focus on the needs of transitional populations and the implications for families with a genetic diagnosis.

Up-to-date guidelines are a priority. Care guidelines, supported by the standardisation of key diagnostic and prognostic tests, are implemented in collaboration with the European Association for the Study of the Liver (EASL) and the European Society for Paediatric Gastroenterology, Hepatology and Nutrition (ESPGHAN).

ERN RARE-LIVER aims to address the significant challenges of clinicians' awareness of rare liver disorders and equitable access to rapidly evolving treatment options.

NETWORK COORDINATOR

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ERN on rare and low prevalence connective tissue and musculoskeletal diseases (ERN ReCONNET)

Rare and low prevalence connective tissue and musculoskeletal diseases (rCTDs) comprise a group of diseases and syndromes which have a considerable impact on patient well-being. They include Ehlers-Danlos syndromes, Systemic Sclerosis, Mixed Connective Tissue Disease, Inflammatory Idiopathic Myopathies, Sjögren's Disease, Undifferentiated Connective Tissue Diseases, Systemic Lupus Erythematosus, Anti-phospholipid Syndrome, Relapsing Polychondritis and IgG4-related disease.

ERN ReCONNET (https://reconnet.ern-net.eu/) is developing a framework for the delivery of high quality, innovative, sustainable and equitable standards of care and practice, which aim to give European rCTDs patients better access to healthcare.

Thanks to the collaboration between full members, ePAG representatives and affiliated partners, ERN ReCONNET has developed new knowledge that is disseminated through peer-reviewed publications and supplements. This new information covers diverse areas such as the development of Red Flags for early diagnosis and of organisational patient care pathways; unmet needs in patient education, expert consensus statements and points to consider in rCTDs.

The network has also delivered a methodology for creating organisational models for rare disease patient care pathways (RarERN Path); a European registry infrastructure for data harmonisation in rCTDs aimed at integrating all existing and newly developed registries on rCTDs across Europe (TogethERN ReCONNET); education and training resources for healthcare professionals and patients; and lay versions of clinical practice guidelines.

ERN ReCONNET has adopted a structured, multi-level Patient Partnership Strategy that embeds patients as equal partners across research, care, governance, education, and strategic planning. This strategy is implemented through concrete mechanisms - such as voting roles in governance, co-leadership of disease groups, co-design of research and educational initiatives, and systematic involvement in identifying unmet needs - ensuring that lived experience directly shapes all network activities.

The close collaboration among the different stakeholders involved in the network represents one of the main added values of ERN ReCONNET, which will continue improving the lives of people living with rCTDs.

NETWORK COORDINATOR

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Azienda Ospedaliero Universitaria Pisana, Italy

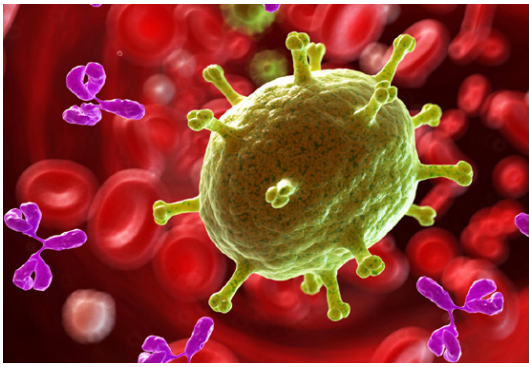
ERN on rare immunodeficiency, autoinflammatory, and autoimmune and paediatric rheumatic diseases (ERN RITA)

ERN RITA brings together 71 leading health care providers across 25 European countries with expertise in the diagnosis and treatment of rare immunological disorders. These constitute potentially life-threatening conditions requiring multidisciplinary care using complex diagnostic evaluation and highly specialised therapies. The network divides these conditions into four sub-themes or work streams - primary immunodeficiency (PID), autoimmune disorders (AI), paediatric rheumatological disorders (PR) and autoinflammatory disorders (AID).

Immunological therapies are advancing rapidly. Polyvalent immunoglobulin therapy has revolutionised the outlook for patients with antibody deficiencies, while targeted anti-cytokine treatments have dramatically improved the lives of those with rare autoimmune and autoinflammatory conditions. Stem cell and gene-based therapies, first developed for primary immunodeficiencies, are now being applied across all disease groups within the network. Most recently, innovative CAR-T cell therapies are emerging as a promising option for selected autoimmune diseases.

ERN RITA (https://ern-rita.org/) builds on the work of the existing European scientific societies which have developed patient registries, clinical guidelines, research collaborations, educational activities and links with patient organisations for all four disease streams.

ERN RITA strives to reduce inequalities in health care faced by patients seeking to access diagnostic testing and innovative treatments such as biologic therapies, immunoglobulin replacement and cellular therapies such as stem cell transplantation. Among its goals are to link pre-existing registries, develop pan-European clinical guidelines, establish a task force of geneticists for quality control of next generation sequencing technology and to find consensus for a common tool for pharmacovigilance in these rare conditions. ERN RITA also aims to convene a task force for the correct use and monitoring of biologic treatments in immune-mediated diseases, to bring together and improve stem cell therapies for patients, to foster collaborations between patient associations, and to bring together paediatric and adult specialists across the four themes.



NETWORK COORDINATOR

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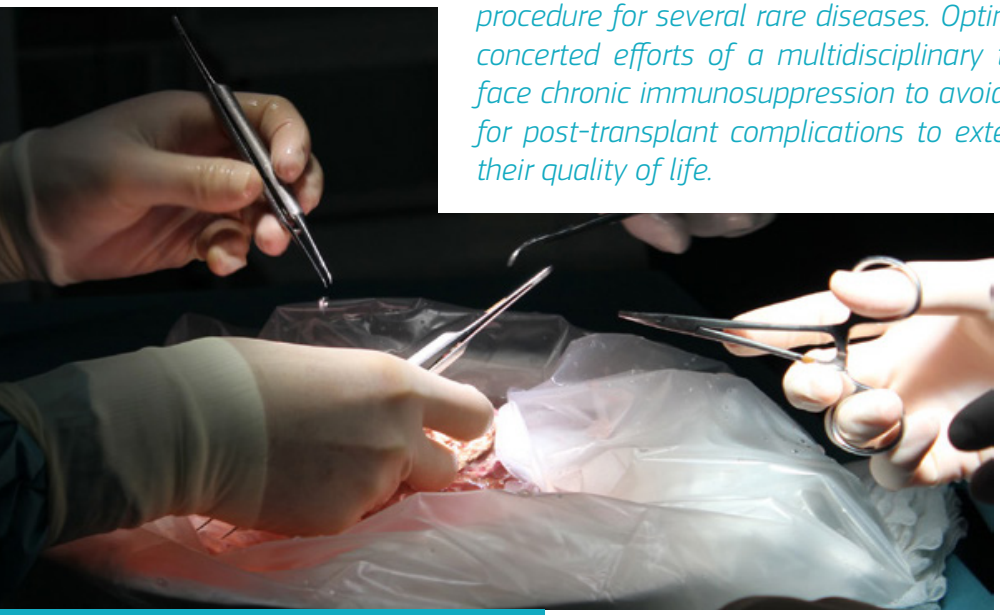
ERN on transplantation in children (ERN TRANSPLANT-CHILD)

Paediatric transplantation (PT) includes both solid organ transplantation (SOT) and haematopoietic stem cell transplantation (HSCT) and is the only curative procedure for several rare diseases. Optimal post-transplant care requires the concerted efforts of a multidisciplinary team. After transplantation, patients face chronic immunosuppression to avoid rejection, which requires monitoring for post-transplant complications to extend children's lifespans and improve their quality of life.



NETWORK COORDINATOR

Dr. Francisco Hernández Oliveros
Co-Coordinator: Dr. José Jonay Ojeda Feo
Hospital Universitario La Paz, Madrid, Spain

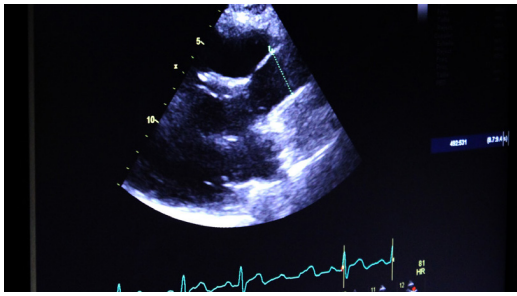
ERN TransplantChild (https://transplantchild.eu/) brings together experts in PT and post-transplantation care to improve outcomes for children and their families. The network aims to reduce both the time spent in hospital and the use of complex, long-term treatments, and it works to improve psychological support services as children transition to adulthood.

The network strives to make the latest techniques and medical, pharmacological and therapeutic advances available, while facilitating the dissemination of harmonised clinical practice guidelines and the development of personalised PT medicine.

ERN TransplantChild seeks to reduce the efforts associated with transplantation – such as re-transplantation and pharmacological treatments - and is harmonising PT care to minimise the risks of post-transplantation complications. Together, Europe's leading PT experts are working to reduce mortality and morbidity related to transplantation in children.

ERN on rare multisystemic vascular diseases (VASCERN)

Rare multisystemic vascular diseases include disorders that affect all types of blood vessels and can involve several organs. These conditions require specialised care from experienced multidisciplinary teams. VASCERN brings together such expert teams across Europe to support timely diagnosis, coordinated management, and access to specialised knowledge.



VASCERN (https://vascern.eu/) aims to strengthen collaboration among expert centres, promote best practices, improve clinical outcomes, support patient empowerment and advance knowledge through clinical and basic research.

The network includes six rare disease working groups: Hereditary Haemorrhagic Telangiectasia (HHT-WG), Heritable Thoracic Aortic Diseases (HTAD-WG), Medium Sized Arteries (vascular Ehlers Danlos Syndrome) (MSA-WG), Paediatric and Primary Lymphoedema (PPL-WG); Neurovascular Diseases (NEUROVASC-WG); and Vascular Anomalies (VASCA-WG). A dedicated ePAG ensures the active involvement of patient advocates in all activities.

VASCERN members produce educational resources for healthcare professionals and patients, which are available on the network's website. These include webinars, e-learning courses, and the 'pills of knowledge' video series.

The network also publishes collaborative research, consensus statements, and clinical decision-making tools such as patient pathways and 'Do's and Don'ts' factsheets to guide diagnosis and care of patients. A Moodle platform is being set up to support structured e-learning for healthcare professionals and patients.

The VASCERN summer school supported by ERASMUS+ trains future healthcare professionals across Europe to advance their knowledge of rare vascular diseases. The alumni programme strengthens this training, giving former participants the chance to visit expert centres and observe how teams deliver specialised care in practice.

A new online space is planned to provide quick access to recommendations and contact details for expert centres across Europe so people can find appropriate care more easily. In parallel, the clinical patient management system (CPMS 2.0) supports secure discussions of complex cases among expert teams and facilitates cross border care. The VASCERN exchange programme also enables visits between member centres, which strengthens collaboration and encourages the sharing of practical experience.

VASCERN continues to build a strong community of healthcare professionals and patient advocates committed to improving access to expert care for people with rare vascular diseases across Europe.

NETWORK COORDINATOR

Professor Guillaume Jondeau
Assistance Publique-Hôpitaux de Paris, Hôpital Bichat, France

ERN Directory

Endo-ERN	ERN on endocrine conditions	https://endo-ern.eu/	info@endo-ern.eu
ERKNet	ERN on kidney diseases	https://www.erknet.org/	contact@erknet.org
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ERN ITHACA	ERN on congenital malformations and rare neurodevelopmental disabilities	https://ern-ithaca.eu/	https://ern-ithaca.eu/contact/
ERN LUNG	ERN on respiratory diseases	https://ern-lung.eu/	info@ern-lung.eu
ERN PaedCan	ERN on paediatric cancer (haemato-oncology)	https://paedcan.ern-net.eu/	ernpaedcan@ccri.at
ERN RARE-LIVER	ERN on hepatological diseases	https://rare-liver.eu/	ern.rareliver@uke.de
ERN ReCONNET	European Reference Network on connective tissue and musculoskeletal diseases	https://reconnet.ern-net.eu/	ern.reconnet@ao-pisa.toscana.it
ERN RITA	ERN on immunodeficiency, autoinflammatory and autoimmune diseases	https://ern-rita.org/	contact-rita@ern-net.eu
ERN-RND	ERN for rare neurological diseases	https://www.ern-rnd.eu/	info@ern-rnd.eu
ERN Skin	ERN on skin disorders	https://ern-skin.eu/	coordination@ern-skin.eu
ERN TRANSPLANT-CHILD	ERN on transplantation in children	https://transplantchild.eu/	coordination@transplantchild.eu
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