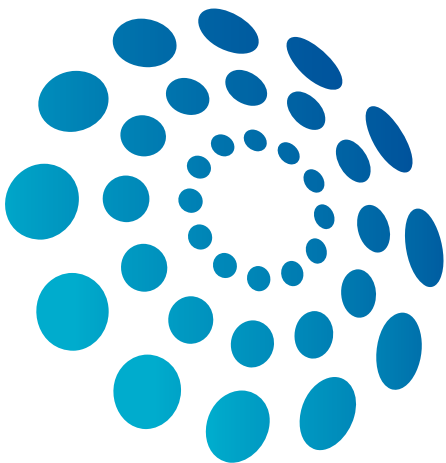




3rd CONFERENCE ON



European Reference Networks

**CONFERENCE
REPORT**

**9–10
MARCH
2017,
VILNIUS**



MALTA EU 2017



**MINISTRY OF HEALTH
OF THE REPUBLIC OF LITHUANIA**

Contents

Executive Summary	3
Introduction	3
Roundtable I Operating European Reference Networks: organisation and management	5
Roundtable II EU Policies and Supporting Actions to the ERN	7
Roundtable III ERNs and national healthcare systems	8
Roundtable IV ERN: The way forward	10

Executive Summary

24 European Reference Networks (ERNs) were formally launched on 9 March 2017. Representatives from the networks and Member States, along with patients and policymakers, gathered in Vilnius, Lithuania, for the 3rd ERN Conference and kick-off meetings (9 & 10 March). There was strong political support for the ERNs which were hailed as an important European success story with the potential to change millions of lives.

Many technical and logistical challenges lie ahead. The ERN IT platform is under development. It will include a collaborative platform, a secure Clinical Patient Management System, and other modules such as a public website, and e-training tools. Work is also under way to address and support the development of interoperable registries for the ERNs. The Joint Research Centre (JRC) and DG SANTE are developing tools to enhance access to, and information about, existing rare disease registries.

ERNs did not appear from a vacuum. They were built on a robust policy and legal framework, and benefit from the work done by EU-funded projects, programmes and networks over the past decade. Now that they are established, several Joint Actions and funding streams are available to support their work. A Joint Programme to align Member State research strategies on rare diseases is under discussion.

The success of ERNs will depend on how well they integrate with national health systems. Member States have a variety of ways to support ERN members and need to exchange experiences on how this can be achieved.

Most healthcare providers are enthusiastic about ERNs but there is some concern about the workload that may be involved. ERNs and Member States will work to raise awareness of the networks among health professionals, hospitals, managers and national agencies.

Looking ahead, as the networks evolve they must find a way to be more inclusive and geographically representative without becoming too large. 'Affiliated Partner' status will provide greater access to ERNs for centres that may not meet the criteria to become full members.

Finally, as patients are to be at the centre of ERNs – as has been the goal from the outset – they and their representatives should actively participate in the advisory bodies of the networks as key partners.

While there is still much work to do, the 'birth' of 24 ERNs is a landmark moment in the history of European voluntary cooperation in the field of health.

Introduction

9 March 2017 marked a historic moment for European healthcare. Not only was it the birthdate for 24 European Reference Networks (ERNs), it ushered in a new era for cooperation in the field of health. High-level speakers emphasised the need for experts to collaborate across borders to improve the diagnosis and care of rare diseases, and applauded progress achieved to date. While it was acknowledged that much work lies ahead to ensure ERNs deliver on their promise, senior politicians described the networks as the kind of 'big idea' that shows European citizens the true value of cross-border partnership.

The challenge

30 million Europeans affected by
6 000 – 8 000 rare diseases

The solution

24 European Reference Networks

- 300 hospitals
- 900 healthcare units

Jean-Claude Juncker, President of the European Commission, sent a video message thanking health professionals and national health authorities for their voluntary cooperation which will demonstrate the EU's added value for its citizens. "European cooperation improves and saves lives," he said. "These new networks will help thousands of Europeans with rare diseases to access the highly-specialised healthcare they need."

The 2011 Directive on Patients' Rights in Cross-border Healthcare is the foundation on which ERNs are built. Not only does the Directive enable patients to be reimbursed for treatment in another EU Member State, it also makes it easier for patients to access information on healthcare and thus increases their treatment options. For patients with rare or complex conditions searching for a diagnosis or struggling to access expert care, the dream of cross-border care is about to become a reality.

ERNs have the potential to become a European success story, according to **Vytenis Andriukaitis, Commissioner for Health and Food Safety**. "We are aware of the complex work ERNs have done to reach across borders and break down silos," he said, noting that network coordinators have achieved a great deal while also doing their demanding jobs as specialists in rare diseases. Dr Andriukaitis paid tribute to the spirit of solidarity and ownership that the Board of Member States has shown in helping to conceive and deliver ERNs. "No single country has the capacity to address all of these diseases alone," he added. "Using technology and telemedicine, the networks will join up information and expertise that are scattered across the EU, ensuring that information travels to the patient."

Speakers in the opening session encouraged ERNs to avail of European funding programmes and instruments, including Connecting Europe, Horizon 2020 and the European Fund for Strategic Investment. ERNs represent an unprecedented opportunity to build registries, produce guidelines, establish clinical pathways, and develop new diagnostics and therapies.

"We have high expectations for ERNs," Dr Andriukaitis said. "If the enthusiasm at this meeting is anything to go by, I am fully confident that these expectations can be met." This will require seamless connections between networks and national health systems, the use of new digital tools, sustainable financing, and stronger access to ERNs for smaller Member States through affiliated partners.

Christopher Fearne, Minister of Health Malta described the official unveiling of the ERNs as "history in the making". He said European cooperation in this area is a major boost for smaller Member States that have neither the critical mass of patients nor the clinical expertise to provide multidisciplinary care for rare illnesses. While Malta has ad hoc bilateral arrangements with some centres of expertise, the Cross-border Healthcare directive – and the ERNs – are fostering the development of a more structured and formal system for improving access to care. "We must ensure that the links between ERNs and affiliated centres are real," he added. "This will make or break the ERNs."

Parliament voices its support

Members of the European Parliament sent video messages from Brussels, adding their voices to the chorus of support for the new networks. **Françoise Grossetête, Member of the European Parliament** and former rapporteur of the Directive of Cross-border Healthcare said ERNs are the realisation of a dream. "With the Commission and Council, the Parliament started to dream of a continent where health centres will share data and knowledge; where European patients and families would have access to the best treatment – wherever they come from." Mrs Grossetête called for more action to ensure the application of the Directive on Patients' Right in Cross-border Healthcare, adding that ERNs should inspire further European cooperation.

Brian Hayes, Member of the European Parliament and leader of the European Advocates for Epilepsy group in the European Parliament, said the meeting signals a new era for people with rare diseases: "ERNs will help those who have, in the past, been left in the dark with rare conditions."

Aurelijus Veryga, Minister of Health, Lithuania said there was no time to lose in using ERNs to bring expertise to patients in need. “Many children are affected by rare and complex diseases,” he said. “These conditions can cause chronic illnesses and, in some cases, are life-threatening.” ERNs give these patients hope that they will have access to the specialist care that they require.

Xavier Prats Monné, Director General, DG SANTE, thanked all who had worked to make ERNs a reality and stressed the need to build the trust required to make them work. “This is a moment of celebration but it would be unwise – having cleared so many obstacles – not to be conscious of challenges we face,” he said. The technological, logistical and structural hurdles that must be overcome would be discussed in detail by the conference, he added.

Highlights:

- Strong political support for European Reference Networks
- Launch of ERNs is a landmark moment but challenges lie ahead

Roundtable I Operating European Reference Networks: organisation and management

At the heart of the ERNs will be the new IT platform that provides the backbone of the networks’ collaboration. **Tapani Piha, DG SANTE**, explained how the Commission is supporting virtual links between ERN members and raising public awareness of their work.

There are three distinct online communication tools. The *ERN Collaborative Platform* supports networks’ activities, facilitating communication between members, document management and event organisation. Crucially, it is not for sharing patient data.

The platform is ready to use and each of the 24 ERNs has a dedicated area in which to organise their work. User support is available through a Helpdesk, a training manual and online demonstrations. An EU login is needed to use the system, and access to specific ERN groups must be authorised by the ERN’s administrator.

Mr Piha urged network members to embrace the platform, add content and encourage colleagues to use it as a collaborative space. “In future, you may feel there is a specific functionality that could be developed,” he said. “We will listen to your feedback and work to refine it.”

3 ways to work together

- ERN Collaborative platform
- ERN Clinical Patient Management System
- ERN public website

Sharing clinical data

The *ERN Clinical Patient Management System* is for sharing clinical data including medical imagery. Building this piece of infrastructure poses considerable technical challenges: no such multi-country clinical system had ever been developed. The first version of the system should be ready in July 2017. It will be built on an existing solution with a proven track record for dealing with this kind of data. All ERNs will use the same system. This allows cross-collaboration between ERNs on cases where expertise from more than one network may be beneficial.

To share patient data, an ERN member must enrol the patient in the ERN system, along with confirmation of their consent to their data being shared. Clinical data can then be shared, followed by a consultation process which leads to clinical conclusions on diagnosis and treatment. Finally, the patient data will be archived so that it might later be used for research purposes, with the patient’s consent.

The Commission is working with the ERN Coordinators’ IT Advisory Group to solve practical challenges such as determining a minimum standard patient dataset and establishing a system for referrals and the patient workflow.

The third element in the IT platform is the ERN public website which will contain information about all ERNs and improve awareness among the general public and healthcare professionals. It should also house clinical guidelines, patient guidance and other outputs produced by the network. The Commission can support ERNs in developing their own websites – for example, by providing free hosting and visual elements – but will not create websites for each network.

Registries and data collection

During an open discussion, a health professional from one of the 24 networks asked for clarity on the timeframe for developing registries. Registry data is of growing interest in healthcare as a source of real-world information on all diseases. As ERNs have the capacity to generate patient data for rare diseases on an unprecedented scale, participants said it was important to define how data would be collected and used.

The Commission replied that archived patient data would represent a basic repository of cases and that more detailed work to ensure the quality, interoperability and usability of data would take place. The priority has been to establish the clinical patient flow. ERN members will work with the Commission to begin capturing patient data in a registry. “For all 24 ERNs to have registries that work well, we need some key principles,” said **Herman Brand, DG SANTE**. “We must define a minimum dataset applicable to all ERNs. Disease-specific fields can be added to this for each ERN.”

An ERN member in the audience said dedicated staff members would be needed to upload data to the Clinical Patient Management System in order to share the workload and ensure good quality data.

A participant asked how ERNs would secure patient consent not only for being treated and having their data shared with consulting clinicians, but also to having their data stored in registries and used for research purposes. “We need standardised protocols for getting consent and to train people in how to obtain consent,” said the speaker.

In response, the Commission said a study had recently been completed on this topic which would map the challenges in obtaining consent. A second phase of that study would result in the development of a toolbox containing consent forms and guidance of users.

A health professional raised potential linguistic issues that may arise when clinicians and patients do not speak a common language. Tapani Piha agreed that this is clearly a challenge: information to patients will be in their language but the IT system itself will be English only. He noted that in the future, e-translation tools may be available.

Coordinators' view

A number of network coordinators shared their experience of establishing ERNs and their vision for how they should evolve. **Alberto Pereira, ENDO-ERN**, described how the 71 members of this network would work together. Chaired by adult and paediatric endocrinologists, the ERN has designated national coordinators to ensure that expertise is correctly disseminated at Member State level. ENDO-ERN has members in 19 countries, including good representation in Eastern Europe. “There are still some gaps but we hope to see those filled through a second call and by welcoming affiliated centres,” he said. “There is no evidence – aside from in surgery – that concentrating expertise in a particular location improves outcomes: we want the expertise to travel.”

Maurizio Scarpa, MetabERN, discussed how ERNs could be cross-linked. The biggest challenges for many rare diseases is securing a diagnosis. For some conditions, it can take an average of 43,800 hours before a diagnosis is found. While the 24 ERNs are organised in a manner designed to reflect how medical specialties are grouped, many patients will require input from several ERNs. “There is crosslinking in nature,” said Dr Scarpa. “Nothing is isolated.” He said ERNs should be at the frontier of ‘network medicine’ – a new way of thinking of health which breaks down silos between disciplines and disease taxonomies. Tools must be developed to link the ERNs, including a shared virtual counselling system that allowed members of different ERNs to discuss complex cases. “ERNs are not a project or a programme they are a *concept* – a revolution in the understanding of rare diseases,” he said. “Don’t think of ERNs as discrete networks but as a large task force for sharing expertise.”

Turning to the question of data ownership, a patient representative asked whether patients will have access to their own data on the ERN IT system. Mr Brand responded that patients legally have the right to access their data and that this would be facilitated, however, ERNs may differ on how to authorise patients in accessing the data. .

Highlights:

- IT tools are being developed for the ERNs, including the Clinical Patient Management System, the heart of the virtual consultation system.
- ERNs are on the frontline for networking medicine, not only internally but by also cross-linking members willing to collaborate with other networks

Roundtable II EU Policies and Supporting Actions to the ERN

John F. Ryan, DG SANTE underlined that ERNs will not operate in isolation. They emerged from a long-standing commitment to rare diseases, a robust policy framework and legislative support for cross-border healthcare. ERNs also owe a debt to various Joint Actions, EU projects and professional societies which have fostered collaboration and knowledge sharing. Now that they have been established, the networks will continue to benefit from a range of related activities, EU services and funding streams.

Jaroslav Waligora, DG SANTE, charted the history of ERNs from the work of the Rare Disease Task Force in 2005, through to the Commission Communication in 2008 and Council Recommendations in 2009, and finally to the selection of 24 networks in 2017. While a great deal of work lies ahead, some foundations have been laid through systems such as the Orphanet database. Orphanet is collecting and disseminating information on rare diseases and providing interoperability tools like rare diseases codification system and rare diseases ontology. Transferring knowledge and expertise from existing European-level networks to ERNs would help to deliver continuity, Mr Waligora said. These include the EUROCAT and SCPE networks and the EU Platform on Rare Diseases Registration. “ERNs are a very important tool but they did not appear from of a vacuum,” he said. “The challenge is to properly integrate ERNs into existing tools, helping them to function properly.”

A key initiative in European collaboration on rare diseases is the RD Joint Action which was built on two earlier actions and runs until May 2018. **Ana Rath, RD Joint Action**, said it is at the intersection of several initiatives including national rare disease plans, registries and the codification of rare diseases. **Victoria Hedley, RD Joint Action**, outlined how it could be of value to ERNs by supporting interoperable data-sharing and the establishment of IT platforms. Through a series of workshops, the Joint Action is exploring models of good practice around data sharing, as well as legal and ethical issues. “The guiding principle for RD Joint Action is that we want to work with the ERNs to find shared solutions to common challenging,” she said. “We must avoid reinventing the wheel and focus on providing support.”

Similarly, the work of the Joint Action on Rare Cancers, taking place over a three-year period, will complement the efforts of three ERNs – specifically those dealing with paediatric cancer, metabolic disorders and solid tumours. **Paolo Casali, Rare Cancer Joint Action** and **ERN EUROCAN** said the goals of these networks have been translated into the work packages of the Joint Action which will serve as a “think tank” for the related ERNs. He added that research should be a fundamental part of the ERNs’ work and should not be separated from healthcare provision.

This was a theme picked up by **Iiro Eerola DG RTD**, who detailed some of the sources of EU funding that could be tapped by the networks. Close to €900 million has already been committed to 160 rare disease projects since 2007. “This research is increasing our understanding of the pathophysiology and natural histories of rare diseases, and supporting the development of new diagnostic tools and new therapies,” he said. “Major investments have been made; now we want to focus on bringing these research results to patients.” In addition to Horizon 2020 funding, the Commission and EU Member States are discussing the possibility of a joint programme that could align national funding schemes to support rare disease research. Such an initiative could provide funding for a virtual platform for coordinating data exchange, as well as training and support for data management.

Big data, huge opportunity

The role of registries in data sharing was a recurring theme through the conference and arose on a number of occasions during open discussions. **Simona Martin, Joint Research Centre**, said interoperability is the key to unlocking the full power of registry data. It is essential, she said, that ERN registries are compatible with one another and with existing databases. The JRC is developing the European Platform on Rare Diseases Registration which aims to improve interoperability of data on rare diseases which is scattered through 600 patient registries in Europe.

“Some registries are operated at local, regional or national levels, while some are managed by individual hospitals,” Ms Martin said. “We want to create a web hub with access rare disease data collections and will provide standards for existing and new registries in Europe.” The JRC can provide ERNs with specific advice on technical, legal and privacy challenges as they collect a wealth of data on rare diseases.

One ERN member in the audience asked who owns the data collected in registries while another asked what data privacy rules apply when transferring data across borders. Ms Martin said the data in registries belongs to the owner of the registry, adding that owners need to comply with national rules on data protection. Special rules apply to European institutions, she noted, meaning that ERNs were in a different situation to all existing registers.

Highlights:

- ERNs did not appear from a vacuum and will have the support of a number of Joint Actions, projects, and funding programmes
- The JRC is developing tools to increase interoperability of new and existing rare disease registries
- A Joint Programme to align Member State research strategies on rare diseases is under discussion

Roundtable III ERNs and national healthcare systems

The role of national funding, private insurers and health professionals was debated in a lively session that highlighted some of the financial and logistical challenges that remain to be solved. Several speakers noted that, with Member States in the driving seat, the success of ERNs will depend on how well they work with national health systems.

“The level of support the networks receive from Members States will determine whether they succeed or fail,” said **Yann Le Cam, Eurordis**. It will be essential that hospital and health system managers appreciate the value of ERNs, and the work of coordinators and members, he added. Mr Le Cam urged ERN members to engage with colleagues to ensure they become a permanent fixture in the healthcare landscape. “ERNs are elite but not a closed club,” he said. “They are an elite that leads; that reaches out; that are an instrument for raising the quality and equitability of care.”

As healthcare systems differ across Europe, there is no ‘one size fits all’ approach to supporting ERN members. Norway provides supplementary funding for national centres of expertise, along with administrative support. **Nora Gamst**, Norway’s representative on the **Board of Member States**, said there are also differences in how individual countries refer patients to centres of expertise. “We need to share experiences with integrating ERNs into national systems,” she said. “We face similar challenges even if we are coming from different starting points.”

This was echoed by **Paul Boom**, the Netherlands’ representative on the **Board of Member States** who said national representatives will need a platform for sharing best practices as the ERNs become embedded in health systems. “Despite the differences in health systems, we have the same goals,” he said. “The infrastructure is there, it’s now a question of how we control the traffic.” On the question of reimbursement, Mr Boom said that in some countries, such as the Netherlands, private health insurers could also play a valuable role in supporting ERNs. “For instance, a patient with a rare disease could have their treatment reimbursed only if they can show they are being treated in a reference centre,” he suggested.

While the ERNs are new, the concept of cross-border healthcare is not. Even before the 2011 directive was introduced, several Member States already had ad hoc arrangements in place allowing some patients to receive specialist treatment for certain conditions. Malta, as an island with a small population, has been referring patients overseas since the 1950s. **Miriam Dalmas**, Maltese representative on the **Board of Member States**, said relationships had been develop between Malta and a number of centres in the UK and Italy. These arose on an ad hoc basis, usually due to geographic proximity or because Maltese doctors established professional links to UK hospitals while training there.

The Maltese experience offers insights for making ERNs work in practice. Interpretation services have been used to overcome language issues; charity and NGO support helped address accommodation costs for patients; and an agreement with an airline was essential to overcoming transportation challenges. Some of these will apply to ERNs, although it was noted that the goal is for expertise to travel rather than patients.

Question time

The issue of funding was high on the agenda for audience members when the time came to ask questions of representatives of the Board of Member States. One ERN member noted that while funding is in place for patients who travel for treatment, it is not clear how 'virtual consultations' could be reimbursed. An ERN leader in the audience said around one third of their working time could be dedicated to virtual consultations at a time when their employer wants them to deal with a heavy local clinical caseload.

Some Member States are also concerned that the additional workload placed on coordinators and other ERN participants. In particular, countries with several ERN coordinators suggested that community funding could be used to compensate them for the time they will spend helping patients across Europe.

Jean-Yves Blay, ERN EURACAN, noted that hosting an ERN member not only benefited people across Europe with rare diseases but generally raised standards of care for all patients at the hospital. By attracting excellent clinicians and improving outcomes, there would be cost savings associated with supporting centre of excellence. "Quality and excellence is cheaper for the health system," he said. "If a patient is well cared for it is money well spent."

A patient representative said patient organisations would also need some support if they are to play an active role in ERNs. Most larger organisations receive national funding but this is not enough to cover the time spent working across Europe. It was noted that the Commission provides funding for Eurordis to help patients with EU collaboration but does not compensate them for national work.

Legal and indemnity concerns were also aired. An ERN member said they feared that advising a patient outside their home country would be illegal as their medical licensed only applied in one country. What would happen, they asked, if a patient sued an external expert for advice they had given. In response, a BoMS representative said that the patients' own doctor remains the ultimate clinical decision-maker and is legally responsible. Even if they consult an external expert through the ERN's virtual platform, liability would remain with the treating physician.

Separately, a number of speakers addressed the role of ERNs in producing and implementing guidelines. It was proposed by an ERN member that Member States might fast-track guidance developed by the networks in order to improve national uptake. As outcomes are demonstrably better in hospitals where guidelines are rigorously applied, it was argued that this would be beneficial to all. It was clear throughout the debate that ERN members and advocates would have to work to make the case the networks would be good for patients, hospitals and health services.

Highlights:

- The success of ERNs will depend on how well they work with national health systems
- Member States need to exchange experiences on how to support ERN members
- ERN coordinators/members are concerned about workload
- Network members will have to 'sell' the ERN concept to managers and colleagues

Roundtable IV

ERN: The way forward

Chair: Xavier Prats Monné (Director General, DG SANTE)

What do healthcare providers expect from ERNs? This was the question tackled by **Arimantas Tamasauskas**, **ERN ERUCAN** and **Member of BoMS for Lithuania**. For providers, the experience of working in an ERN may vary as the number of members, and the breadth of diseases covered, varies considerably. The smallest ERN has 18 members while the biggest has 73. However, all providers share a vision for how the networks should operate. They expect good cooperation between members; to receive or provide second opinions on rare or complex cases; to collaborate on research projects; and to use state-of-the-art technologies.

“Most healthcare providers are very enthusiastic about ERNs,” he said. “By participating, they hope to gain recognition, attract patients, attract professionals, and to use advanced diagnostics and treatment modalities.” Some remain sceptical, citing concerns about the investment required and the long-term sustainability of the networks, but most take a positive view.

Christopher Chapple, **eUROGEN**, is decidedly enthusiastic. He said that “brave surgeons and brave patients” share a commitment to improving outcomes across Europe. “While there is plenty of work ahead, I believe that *where there’s a will, there’s a way*,” he added. Dr Chapple returned to the question of clinical responsibility which was raised in earlier sessions. In his view, the issue was less complex than some might fear. “The doctor is responsible for their own patient,” he said. “Just as we consult literature and take advice from colleagues, we will seek input from other ERN members through the IT platform. But at the end of the day you make decisions about how to diagnose and treat your patient.”

Dr Chapple also called on ERN members to embrace the power of technology to spread their expertise and to build virtual multidisciplinary teams. This can be done by sharing cases on secure IT platforms and, with consent from the patient, live-streaming surgery on YouTube to maximise the benefit for surgeons and patients everywhere. Raising outcomes for people with rare conditions would be a key success factor for the ERNs.

How else might success be measured after their first five years? **Till Voigtlander**, **Chair of the ERN Board of Member States** listed some of the imperfections in the newly-formed networks and the challenges that these pose. For example, there is a geographical imbalance in most ERNs and some have already become bigger than some had initially anticipated. Finding a way to become more inclusive without creating unwieldy mega-networks will be a key test. “In five years’ time, I expect a further refining and shaping of the networks,” he said, adding that the optimal operational size would become clearer as the ERNs get up and running.

A definitive solution to the reimbursement issues must emerge in the coming years if healthcare providers are to be paid for virtual consultations in a way that operates smoothly from the patients’ perspective. “The relationship between costs and improvement of healthcare provided will be crucial for payers when judging the success of ERNs in 2022,” he said.

Patient perspectives

The needs of healthcare providers and Member States were well ventilated at the conference but, as ERNs are designed to be patient-centric, the final presentations came from two patient representatives.

Rebecca Tvedt, patient representative in **ERN BOND**, shared the story of her own diagnosis with a severe, rare bone disease in 1975. In the absence of ERNs – and the Internet – Tvedt’s parents read library books and travelled to meet experts in England and the US. Her condition is so rare that Tvedt only once met a child with the same disorder. “I felt alone and different – quite a common feeling for people with rare disorders.”

She described how she became her own top expert, often enlightening health professionals who had little knowledge of her disease. “I had become an expert without the salary,” Tvedt said wryly. Patient organisations are often volunteer-led, run by people working from their kitchen table with very limited resources. It is important that patients are seen as equal partners in ERNs and given the support they need to play an active role. If reality meets the aspiration of all who have supported the evolution of the networks, thousands of people will benefit from unprecedented access to expertise. “We can’t make rare diseases common but can make access to diagnosis and treatment common to all,” she said.

Avril Daly, ERN-EYE and **CEO Retina International**, and **Eurordis** charted the long journey that led to the birth of ERNs. She has been involved in work leading up to the establishment of the networks for more than a decade. “It has been eventful, with many twists and turns, but when we look around and think of 8,000 diseases represented in 24 networks we can agree all the sleepless nights were worth it,” she said.

As well as consulting over 5,000 eye care specialists, Retina International held roundtables and patient symposiums to help set the priorities of ERN-EYE. Now, as the network begins its work, Daly’s goal is to ensure patient expertise is visible across Europe so that their voices are always at the table. “We will do all we can to populate ERNs with the patient experts that are required,” she said. “Patients have much to offer and we all have much to learn.”

End of the Odyssey

During an open discussion, a patient representative expressed confidence that the networks would “reduce the diagnostic odyssey” that many patients face when searching for answers about their condition. Another patient representative also celebrated the launch of the ERNs but called on healthcare providers to view patients as true partners in this new collaborative system. This was echoed by others who reiterated the need for financial support for patient representatives.

Closing the conference, **Xavier Prats Monné, Director General, DG SANTE**, thanked all who have given their time and vision to turning ERNs from concept to reality. “Your work is extremely encouraging and we in the Commission can promise our continued support in the years ahead,” he said.

Highlights:

- Most healthcare providers are enthusiastic about ERNs; some have concerns
- Finding a way to become more inclusive without creating unwieldy mega-networks will be a key test
- A way to manage reimbursement for virtual consultations must be found
- Patients should be treated as equal partners in the networks and supported accordingly

ERN leaders receive certificates from Commissioner

As the conference closed, the coordinators of all 24 ERNs received certificates from Vytenis Andriukaitis, Commissioner for Health and Food Safety, formally recognising the networks. The Commissioner paid tribute to the dedication, enthusiasm and professionalism that members have shown in overcoming many challenges.

“This is not the end – it is only the end of the beginning,” he said. “Today we have reached a milestone but the true measure of our success will be in bringing benefits to patients. Our journey starts now.”

