



**EUCERD JOINT ACTION
WORKSHOP ON RARE DISEASE
EUROPEAN REFERENCE
NETWORKS
(RD ERNS)**

Newcastle, 25-26 November 2012



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INTRODUCTION

This workshop was conceived in the context of the ongoing activities of the European Union Committee of Experts on Rare Diseases (EUCERD). It was organised by the EUCERD Joint Action (EJA) which supports EUCERD in its work, and was enabled by European Commission (EC) funding.

The workshop built upon the outcomes of an informal workshop on the topic of European Reference Networks (ERNs) for Rare Diseases (RD) held on 19th June 2012, which brought together the different stakeholders involved in this issue, in order to discuss a first draft set of EUCERD Recommendations for ERNs for RD. Following further debate at the 5th Meeting of the EUCERD (20th-21st June 2012), the Joint Action organised this present workshop on the topic of RD ERNs, held on 25th and 26th September 2012 in Newcastle-upon-Tyne, UK.

Main objectives:

- Review and pre-finalise the current Recommendations for RD ERNs, for approval and adoption by the EUCERD at its 6th Meeting in November 2012 or at its 7th Meeting planned for January/February 2013.
- Consider how the EUCERD Joint Action and EUCERD members can support the European Commission and MS in the implementation of the final recommendations.

Background

To date, many networks for rare diseases have been established, primarily with EU funding (please refer to the documents in Appendix iv-viii). These 'pilot' projects have typically adopted an *ad hoc* approach to the issues affecting their disease area. Although work on the designation of national centres of expertise (CEs) for RD has been going on in parallel, there has been a lack of systematic engagement of networks with the relevant national centres; indeed, in many Member States (MS) there are currently no designated national centres with which to engage. Consequently, although the networks have been developing valuable tools and resources for the RD community (including patient registries, diagnostic pathways and standards of care) such good practices have not been broadly disseminated at the national or European level. This is a concern, as the value of the networks has been

demonstrated across different RD groups through indicators such as improved diagnosis and care for patients, development of patient registries, telemedicine solutions and partnering in therapy development programmes. The sharing of these tools and expertise, where this has been pursued, has supported the research agenda and, crucially, has led to better medical and social care for those RD patients. One major problem common to all of these networks, however, has been sustainability and how to successfully plan for this.

The Starting Document

The draft *EUCERD Recommendations on ERNs for RD* distributed to delegates ahead of the workshop were based on preliminary work by the Rare Disease Task Force and previous EUCERD discussions (as above). They touched upon the many challenges facing the development of ERNs: the creation of a clear and transparent mechanism for the designation, leadership and governance of ERNs; further capacity and skills building; a system to allow the sharing of tools and resources to support ERNs; and the establishment of an external quality assurance scheme and common indicators for ERNs.

Format of the workshop

This was a very practical, discussion-based workshop. Though structured into thematic areas of stakeholder discussion, it was emphasised by the organisers that the entire two-day event would focus on revising the current draft recommendations. To structure and stimulate the debate, a number of delegates delivered short presentations on relevant areas of interest.

WORKSHOP REPORT

Welcome from Kate Bushby (KB)

As EJA Co-ordinator KB extended a welcome to all participants and reiterated that although all sessions will incorporate brief presentations, the organisers intend this to be a very practical, discussion-led workshop focussing on re-drafting the existing *EUCERD Recommendations on RD ERNs*. It was pointed out that these currently contained some important gaps which required tightening for the specificities of rare diseases. Given the fact that the ERN debate sits amidst a dynamic and changing EU environment, it was deemed useful to begin with some context regarding the Cross-Border Healthcare (CBHC) Directive (Directive 2011/24/EU), Article 12 of which describes the establishment of ERNs.

European Commission update on the ERN process in the context of the Cross Border Healthcare Directive – Jaroslaw Waligora (JW)

JW agreed that the concept of ERNs belongs to a rapidly changing world, and it is helpful therefore to clarify how the workshop delegates can contribute today and who the other key players are. Directive 2011/24/EU is now being implemented, but it needs to be transposed into national law by every MS. The deadline for this (ongoing) process is October 2013. The EC has asked that criteria be defined for concepts raised in Article 12 (namely ERNs and CEs) and for how the whole process will work. ERNs are a new concept - previously, individual projects were set-up, whereas now we are building new parts of an overarching healthcare system. The Directive requires the EC to address, via the **Delegated Acts and Implementing Acts**, the following criteria:

- The Delegated Acts will provide criteria for CEs and ERNs. So they will define:
 - a) the criteria a national centre needs to meet to become part of an ERN; and
 - b) the criteria a network needs to fulfil in order to be designated an ERN
- The Implementing Acts will define criteria for establishing, governing and evaluating ERNs, as well as addressing how they will be financed.

These two processes are very different. The Commission retains ultimate responsibility for composing and adopting the Delegated Acts, with advice from the CBHC Expert Group (composed of representatives from the MS). The current deadline for this is Oct 2013, to coincide with the transposition of Directive 2011/24/EU. The EC will begin drafting the Implementing Acts in December, again following advice from the CBHC Expert Group and also the Committee of the CBHC Directive. The latter group will ultimately *vote* for the Implementing Acts. The work currently being carried out on ERNs for rare diseases is unique to this area, as the CBHC Directive is the first legally binding document of its type.

A few key concerns were then highlighted by JW, regarding RD ERNs, as examples of the kind of issues the workshop should discuss: the importance of co-ordinating ERNs and enabling the exchange of information (and where necessary, patients) between networks; the need for some sort of governance structure to oversee ERNs; the question of having multiple levels of entry for healthcare professionals; and the integration of research activities alongside the mainstream goal of healthcare provision.

Discussion Session – CBHC Directive and CEs

It was agreed the EC update from JW had made the gaps a little clearer, as far as what was required in the Recommendations. The group were urged to focus on what *ERNs* look like, as opposed to *CEs* (which for RD has already been covered by the *EUCERD Recommendations on Quality Criteria for Centres of Expertise for RD in MS* – appendix iii). It was agreed that the positive experiences and contributions of the pilot networks must be utilised and developed, whilst taking note of areas for improvement and missed opportunities, in order to encourage sustainable systematic engagement with healthcare systems. There was some debate as to how this EJA working group should interact with the CBHC Expert Group. Several of those assembled expressed a preference for a ‘back and forth’ approach to collaboration here. JW, representing the Commission, explained that it is not possible to *formally* link the groups, as EUCERD is not involved with the CBHC Directive directly; however, given the necessity that the CBHC Expert Group is familiar with the work EUCERD is producing on RD, informal cross-talk seems sensible and is certainly desired on both sides. The participants agreed that they should convey a specific RD message to the

CBHC Expert Group, to differentiate from the advice of others, and this should include a fairly radical vision of what an RD ERN should look like.

The debate moved from how EUCERD's work will complement/supplement that of the CBHC Expert Group to the question of components of an ERN. Delegates debated whether or not new CEs were needed for future ERNs. Some participants suggested the most sensible approach would be to network existing centres first and then create CEs a) in MS where there are none and b) where a particular RD theme is not covered. The group was advised to take care to refer to *enhancing/building upon* what exists already, as opposed to emphasising current *inadequacies*.

Presentation of the Patient Perspective on RD ERNs – Christel Nourissier (CN)

CN presented the EURORDIS position on RD ERNs. She began by considering the components necessary in a RD ERN. It was emphasised that there are specific challenges here related to the specificities of RD, therefore it is essential that all stakeholder groups are involved – not only CEs but healthcare providers, diagnostic laboratories, patient organisations (POs) and crucially also specialised social services (SSS), especially in the long term (the French experience has shown there is a limit to what can be achieved in hospitals, and there must therefore be coherence between hospital care and SSS for RD). EURORDIS felt the term 'healthcare providers' needs to be further defined in this context – individual medical experts in any given MS must be recognised by patients, national authorities and also a corresponding ERN following *common defined criteria*.

The presentation drew attention to a particularly notable conclusion of the EUROPLAN 1 national conferences, namely that the situation for small MS demands special attention. Establishing CEs in some places is not feasible. In such cases there is instead a call for establishing a network of individual medical experts dealing with RD whilst promoting cross-border care when appropriate. In these instances it is particularly important that healthcare providers/medical experts are integrated with the ERN closest to their speciality/disease. At the national level, healthcare providers should be encouraged to create or join a multidisciplinary team.

It was emphasised that POs wish to be recognised as equal partners and want to be involved in the governance and evaluation of RD ERNs; however, they are realistic about the scope,

given the fact that patient groups do not yet exist for *all* RD. Regardless of the challenges, POs have considerable experience and understanding of the realities of living with RD, which will bring added value for ERNs. EURORDIS' proposal is to adopt a step-wise approach to the creation of RD ERNs, incorporating an organised network of POs. POs currently involved in the activities of a CE must remain so, and should advise future ERNs. As ERNs develop they should encourage the creation of European Federations for their disease areas (EURORDIS can offer support here). Finally, the presentation addressed the issue of how to support RD patients without diagnoses. The feasibility of having transversal projects across ERNs for undiagnosed patients must be considered, and the NIH model of the Undiagnosed Diseases Program was proposed as a potential source of guidance here.

Discussion Session – access to ERNs, criteria, scope and governance

The challenges faced by smaller MS were discussed at this juncture. It was acknowledged that creating CEs is not practical in some places, although it was pointed out that the size of a country does not matter so much if you focus on healthcare pathways – an individual expert will be linked to a network with a much greater range of expertise, which is then at the disposal of patients in a small MS. It was agreed that networks must make particular efforts to engage with smaller countries. In light of this debate, it was suggested the group recommend that one function of an ERN should be to support medical experts without a CE, who would be enabled to participate in the network and attend training etc as required.

The group debated how necessary it is to involve doctors/individual experts in ERNs (when CEs *are* available). The experience of those in disease-specific networks (e.g. porphyrias) has shown such participation to be crucial. The consensus was that there should be sufficient flexibility to enable 'healthcare providers' to participate in RD ERNs on some level, even if they do not fulfil the criteria to be considered CEs.

The criteria for including CEs in ERNs were briefly touched upon here. It was emphasised that, as already discussed, having a clear quality assurance scheme for CEs is essential (as is clarification of the consequences if standards are not met.) Furthermore, simply *designating* CEs (where this is possible) is not enough – the French experience has shown the importance of subsequently raising awareness of these centres amongst medical professionals. Nonetheless, CE designation remains of course a MS responsibility. Details of

the CE system in Germany were provided (it was explained that a German CE is not a single location but instead integrates different levels of expertise).

Whilst debating the scope of ERNs, an important distinction was raised - diagnostics and treatment are universal issues and ERNs are therefore perfectly suited to support patients' needs in these respects; however, delivery of care and social services are *local* issues. Some participants suggested CEs should therefore be multidisciplinary, to ensure this important part of the patient experience is involved somehow in ERNs. At this juncture the group was reminded that specialised social services (SSS) cannot officially be covered by ERNs as they are explicitly excluded from the scope of the CBHC Directive. Notwithstanding this legalistic barrier, the group was in favour of *recommending* that SSS be involved somehow, believing their unique importance to the RD field must be emphasised (and that it would be neglectful not to do so). It was agreed that although the first stage for any patient is diagnosis and treatment - and some plans will likely focus only on these areas initially - integrating specialised social services is unavoidable in the long term.

The involvement of POs was then debated, in view of the EURORDIS presentation. It was suggested that having POs participate in ERNs might create greater harmonisation and cooperation amongst POs. However, some participants stressed the need for criteria to determine which POs could participate in ERNs (as after all there will be criteria for CE participation). It was made clear that association with a PO should *not* be envisaged as an essential criterion for an RD ERN to fulfil – this condition would only apply where an appropriate PO exists. Nonetheless, the value POs can bring to RD ERNs was widely acknowledged, and representatives of EURORDIS in particular were consequently strongly in favour of involving them as far as possible in governance.

The last area of debate in this session focused on the challenges of providing optimum care for patients without a diagnosis. It was emphasised that there are actually two types of RD patients in this category – those who are not diagnosed but *will be*, in time, and those for whom a diagnosis is not possible given current medical expertise. Many participants felt that RD ERNs should have a responsibility to care for undiagnosed patients (regardless of which of the two categories above they fall into) - in such cases effective cross-talk *between* ERNs will be absolutely crucial. The importance of a diagnosis to patients and their families was acknowledged; in view of this, several individuals stressed the need to re-test people at

regular intervals, to give patients the best chance of being finally diagnosed. Access to and knowledge about such testing could be facilitated by an ERN.

Session 2

The Role of Genetics in the ERN Structure – Helena Kääriäinen

The presentation began with an illustration of how CEs for different sorts of RD would feed into overarching ERNs appropriate to their specialism. This structure would work very well for patients with clear clinical and/or genetic diagnoses. But how effectively would this CE/ERN interplay function in cases concerning *undiagnosed* patients, or if the disease is *very* rare and consequently has no dedicated CE or ‘natural’ ERN? Who, along with the referring clinician, coordinates the care of such patients? Perhaps genetic centres could function as CEs for undiagnosed patients and those with genetic mutations beyond the present understanding of clinicians – in which case, which ERN would the genetic centres link to? The Belgian national plan was hailed here as potentially a very good model, because it aims to integrate every stakeholder. At its heart is the triangle of CEs, Centres of Human Genetics (CHG) and a Liaison Centre for RD (which is essentially a place for people without a diagnosis).

The presentation concluded by considering what is required in terms of horizontal ERNs. Diagnostic support, such as that provided by Dyscerne, is a very important example to consider. Also key is quality assurance in genetic testing, which is a universal issue. EuroGentest has taken care of this very well thus far, but next generation sequencing (NGS) will demand greater consideration of how future technological advances will impact genetic testing strategies and standards.

Discussion Session – scope, transversal elements, communication

The group considered whether ERNs should be disease specific (e.g. concerned with neurology, endocrinology etc.) or technique/therapeutic specific. It was reported that this has been considered by the Commission, and ultimately both kinds will probably be established. The merits of embedding shared tools (such as tele-medicine), which would be common to all ERNs, were emphasised. In the RD field, the tools provided by networks such as Dyscerne and EuroGentest were hailed as good examples of services that benefit patients

greatly. Some participants stressed the difficulties faced by clinicians in knowing where to send heterogeneous patients with many and varied problems. The importance of not viewing a diagnosis as an 'end' to the process was emphasised – there must be flexibility to transfer patients across ERNs as required. It was reported that in France a dysmorphology network provides care and rehabilitation for people without a diagnosis. Most participants were vocally supportive of the idea of embedding some sort of transversal quality assurance scheme in RD ERNs. It was agreed that the group should recommend a 'theme' on quality assurance in each ERN, which could work in practice via a structure such as EuroGentest (for genetic testing in particular). The importance of utilising the resources currently available and incorporating the outputs of past and current EU projects into all future plans, was reiterated here.

Regarding communication within and between ERNs, the participants agreed the importance of providing forums for the exchange of knowledge and experience, such as expert conferences. However, some workshop participants also emphasised the pressing need to supplement this sort of inter-expert information exchange with a willingness on the part of individual MS to formally acknowledge and adopt guidelines for best practice etc., in order to maximise the scope of outputs such as care guidelines. Ideally, we would have a situation in the EU whereby one MS adopting such documents would lead to the others following suit. How to recommend such an approach without impinging on MS autonomy was debated. It was suggested that the logical means of achieving greater harmonisation in this respect would be to collect proper comparable data. Perhaps in the future, recommendations should state that the group supports a means of MS fast-tracking resources such as care guidelines where there is strong evidence of their effectiveness (the cross talk of the EJA with EUnetHTA should help to facilitate this).

The Scope of Centres of Expertise for RD – Charlotte Rodwell (CR)

CR delivered an update on the Orphanet survey on the scope of CEs for RD. She explained the context - at the 5th EUCERD meeting the Committee members expressed a desire to access Orphanet's lists of CEs for their own MS. In July 2012 CEs were sent a questionnaire designed to ascertain the scope of their activities, in terms of RD coverage. It was reported that to date 337 responses had been received (although it was explained that the French

CEs were not included in this exercise, on the grounds that Orphanet already had sufficient knowledge of their activities). The deadline for all CEs to respond is the end of 2012, and it was explained that the questions were based around the *EUCERD Recommendations on Quality Criteria for Centres of Expertise for RD in MS* (appendix iii).

Charlotte emphasised that from the data collected it is neither possible nor desirable to envisage a separate CE for each RD. This is due to a variety of factors: the sheer number of RD; the size, population and resources of some MS; limited expertise; and commonalities between diseases.

The methodology used in the exercise was explained. The CEs were approached based on their inclusion in the Orphanet database (appearing either as officially designated CEs or else recognised in some other way by the MS). The essential aim was to analyse the disease coverage of each CE. To this end, RD were grouped by medical areas such as kidney diseases, immune system deficiencies and hereditary metabolic diseases. Under these areas the team devised a hierarchy of groups, sub-groups and single diseases.

For example, under the medical area of ‘hereditary metabolic diseases’:

- some countries opted to cover a group called ‘hereditary diseases of metabolism’
 - some opted to cover a sub-group like lysosomal diseases
 - some counties covered a single condition such as Fabry Disease.

It was concluded that many CEs actually fit into the traditional organisation of medical healthcare, with 12 groups of diseases (such as rare pulmonary diseases and immunodeficiency disorders) being covered by centres in two or more countries. However, some grouping outside the traditional areas is clearly needed – countries have identified a need for CEs covering lysosomal diseases and mitochondrial diseases, for example. The results show that diseases can be organised by group/subgroup for monosystemic diseases but special attention must be given to multisystemic diseases with no dominant speciality.

Discussion Session

A brief discussion session followed the presentation. The results of the scoping exercise are eagerly anticipated by all, although some participants felt it would have been interesting to include the French centres, to establish how fully they are actually meeting the EUCERD

criteria. Others believed it would be illuminating to see how many CEs on Orphanet's database have actually been officially designated by their respective MS. The issue of reliability of self-declared results was raised, but it was agreed that the number of returns so far is in itself a cause for optimism.

Session 3: Networking the networks to support MS in recognising resources already available – Discussion Session

The participants discussed how best to utilise the resources already in the field when establishing the future ERNs. Some ERNs for (non rare) diseases, such as chronic diseases, will probably be more focused on procedures and techniques. The PO representatives emphasised that when it comes to prioritising RD ERNs we must start with what already exists; subsequently, that first wave of ERNs will have to expand over the next 3-5 years, to become progressively more inclusive of experts and conditions. This does not mean we ultimately end up with one 'super ERN'; however, we need to accept that envisaging 'one ERN per disease' clearly will not work in this field. The EURORDIS vision encompasses some 20 or 30 disease areas to cover all RD. The challenges for MS who only wish to have for example one or two CEs for RD, were discussed. In this context, there would need to be particular people within those CEs who could interact with different ERNs. The group consensus was that there should be calls for ERNs and applications should be accepted in the first 'round' based on excellence and maturity. The participants came up with two principles here: firstly, as a RD community, they believe in the prioritisation of rare diseases when it comes to designating ERNs; secondly, they recommend that ERNs emerge in a step-wise manner, based on maturity and excellence.

The group agreed that monitoring committees/governing bodies should oversee ERNs, and it was deemed vital that RD expertise should be embedded here too. A single monitoring committee would probably not suffice, and external experts would need to be brought in as required – flexibility again is key. It was suggested the application for becoming an ERN should be quite comprehensive, and should require a clear description of plans for core components such as patient registries. The participants discussed the prospect of recommending that it be a key function of an RD ERN to deliver and share resources such as

registries and care standards, and debated whether ERNs should be organised by diagnostic and systematic areas, each covering a wider range of diseases.

The group agreed it would be useful to collect case studies of initiatives which have worked well in the past. The debate concluded with a joint accord to recommend that RD ERNs should meet the needs of all RD patients, as it is clear that *all* patients are a priority in the RD field.

Patient Perspective on RD ERNs (Funding and Indicators) – Christel Nourissier (CN)

CN presented the remaining slides of the EURORDIS presentation on RD ERNs, focusing on the topics of Funding and Indicators. It was argued that funding cannot be postponed for ERNs, and that it should cover the core activities of a RD ERN (i.e. the implementation of building blocks, the scope of activities, personnel such as coordinator of the network and registry manager, etc.). The budget should be comparable amongst ERNs to avoid major discrepancies between allocations to HR, equipment, databases etc. EU funding must be flexible, and it will be necessary to impose a dynamic process for the accreditation and evaluation of ERNs. Regarding indicators, EURORDIS proposed that medium and long term indicators of various kinds are required: process indicators can demonstrate short term results; outcome indicators can lead in the long term to earlier diagnoses and improved mortality and morbidity; and impact indicators can assess quality of life for patients. It was suggested that a multi-stakeholder group be tasked with defining specific indicators for each of these three categories (which together will help to demonstrate the importance of ERNs).

Discussion Session – Funding and Indicators

It was pointed out that the core activities of RD ERNs would need to be defined very carefully here, given the funding implications. Participants were reminded that core registry functions and CEs are funded by MS, although it was agreed that the coordinators of ERNs must be funded by the EU, on the grounds that people cannot perform such roles on a voluntary basis, in their spare time. Disease specific data collection in addition to the potentially limited and generic RD data collected by MS could be the responsibility of an ERN.

The debate then moved towards further talk on networking the networks. The view was expressed that the Commission must cover the costs of networking between networks. It was revealed that the EC has not yet decided what funds will be available for such purposes, since the budget for 2014-2020 has not yet been finalised. Participants expressed a desire for permanent funding for ERNs, in view of the need to make these structures sustainable - it was agreed that this should be recommended.

Turning to the theme of Indicators, it was agreed that the group should recommend a need for short and long term indicators, which could be generic, and would then be related to the core components of the networks. This is in view of the central importance of indicators in demonstrating the real added value of this Europe-wide approach, which will be essential when the next health programme is being planned. ERNs need to capture as much data as possible, to enable those involved to make precise statements regarding the impact of ERNs on the RD field.

The specific headings around which recommendations would be drafted were agreed:

- Scope and overarching vision (inclusiveness)
- Target Audience/Groups
- Overarching diseases and their specificities
- Thinking about the patient
- Designation and prioritisation of ERNs (so how we see prioritisation in terms of inclusivity, how to assess etc.)
- Thinking about stakeholders (so we have CEs, the coordinating site, affiliated members, PO input etc.)
- Scope of the Recommendation (diagnosis, access to therapy, clear mechanisms for patients to travel if need be)
- Definition of the core areas/core functions (and consideration of how those might be common across ERNs)
- Funding and Indicators (sustainability, resources the core functions require)

Next Steps

It was agreed that a new draft of the *EUCERD Recommendations on RD ERNs* would be distributed to participants of this workshop within 1 week. After review, feedback would need to be received by the leaders of the Integration work theme in time to revise the document and distribute to the EUCERD members ahead of the 6th meeting on November

14th - 15th 2012. Following debate and comments over the course of this meeting, a final version of the ERNs will be drafted and distributed to EUCERD members, with the aim of formally adopting the Recommendations at the 7th EUCERD meeting on January 31st 2013. This final document also needs to be distributed to the CBHC Expert Group, which is **meeting in December 2012.**

APPENDIX

I) AGENDA

Tuesday 25th September 2012

- Welcome and overview of the aims of the workshop
- European Commission update on the ERN process in the context of the Cross Border Healthcare Directive – *Jaroslav Waligora*
- Discussion: Review and revision of the current draft Recommendations, to be compatible with Directive 2011/24/EU
- Presentation of the Patient Perspective on RD ERNs – *Christel Nourissier*
- The Role of Genetics in the ERN Structure – *Helena Kääriäinen*
- The Scope of Centres of Expertise for RD – *Charlotte Rodwell*
- Discussion: Tackling the process of prioritisation in creating ERNs. Update on current efforts in definition of CEs (including Orphanet survey, EJA WP7), consideration of scope, access and components of RD ERNs, including transversal elements.

Wednesday 26th September 2012

- Discussion: Networking the networks to support MS in recognising resources already available
- Presentation of the Patient Perspective on RD ERNs: Funding and Indicators – *Christel Nourissier*
- Final session and wrap-up to include plans for how the EJA and EUCERD members can support the implementation of the ERN recommendations once adopted?

II) LIST OF PARTICIPANTS

Kate Bushby	Newcastle University, UK
Joan Luis Vives Corrons	ENERCA
Dorica Dan	EURORDIS
Victoria Hedley	Newcastle University
Veronique Heon-Klin	Federal Ministry of Health, Germany
Helena Kääriäinen	National Institute for Health and Welfare, Finland
Odile Kremp	INSERM
Yann le Cam	EURORDIS
Stephen Lynn	Newcastle University
Flaminia Macchia	EURORDIS
Maria Mañú Pereira	ENERCA
Christel Nourissier	EURORDIS
Francesc Palau	CIBERER
Samantha Parker	Orphan Europe Recordati
Bianca Pizzera	EURORDIS
Gabriela Pohla-Gubo	EB-CLINET
Charlotte Rodwell	INSERM
Luciano Vittozzi	National Centre for Rare Diseases, ISS
Till Voigtländer	Clinical Institute of Neurology, Austria
Jaroslav Waligora	DG SANCO
Cornelia Winten	Hessian Ministry of Social Affairs

Apologies for Absence from Ségolène Aymé and Gemma Gatta

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