A Proposed European Reference Network For Rare Congenital Malformations And Intellectual Disability

Coordinated By Jill Clayton-Smith
The Principle Of ERNs; Third Health Programme Specific Objective 4

• To facilitate access to better and safer healthcare for EU citizens, including cross border healthcare

• To increase access to medical expertise and information for rare conditions

• To facilitate application of results of research

• To develop tools for the improvement of healthcare quality and patient safety
Call for European Reference Networks issued 16.3.16

• Broad overarching networks, as defined by EUCERD

• At least 10 members from at least 8 member states but no official limit. APPLICANTS ARE HEALTH CARE PROVIDERS

• HCPs must be endorsed as experts in the field by their Member States
• Affiliate members/second wave members come later

• The initial application is for a Framework Partnership Agreement, for 5 years, simultaneously submit grant application for first year

• Application for funding will be one year at a time thereafter, maximum of 200,000 Euros/year. 40% co-funding
Proposed Operational Criteria Of An ERN

The following table summarises the themes covered in the Operational Criteria for the Network and Healthcare Providers.

<table>
<thead>
<tr>
<th>Themes in the Operational Criteria</th>
<th>Network</th>
<th>Healthcare Providers</th>
</tr>
</thead>
<tbody>
<tr>
<td>Themes</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Network</td>
<td>Establishment of a European Reference Network</td>
<td>General Criteria:</td>
</tr>
<tr>
<td></td>
<td>Highly Specialised Healthcare</td>
<td>- Patient Empowerment and Patient-Centred Care</td>
</tr>
<tr>
<td></td>
<td>Governance and Coordination</td>
<td>- Organisation, Management, and Business Continuity</td>
</tr>
<tr>
<td></td>
<td>Patient Care</td>
<td>- Research, Education and Training</td>
</tr>
<tr>
<td></td>
<td>Multidisciplinary Approach</td>
<td>- Expertise, Information Systems, and e-Health Tools</td>
</tr>
<tr>
<td></td>
<td>Good Practice, Outcome Measures, and Quality Control</td>
<td>- Quality and Safety</td>
</tr>
<tr>
<td></td>
<td>Contribution to Research</td>
<td>Specific Criteria:</td>
</tr>
<tr>
<td></td>
<td>Continuous Education, Training, and Development</td>
<td>- Competence, Experience and Outcomes of Care</td>
</tr>
<tr>
<td></td>
<td>Networking and Collaboration</td>
<td>- Human Resources</td>
</tr>
<tr>
<td>Assessment</td>
<td>Each criterion is rated <strong>once</strong> for the overall Network.</td>
<td>- Organisation of Patient Care</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- Facilities and Equipment</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Each criterion is rated <strong>individually</strong> for each Healthcare Provider within the Network.</td>
</tr>
</tbody>
</table>
A Proposed ERN For Rare Congenital Malformations and Intellectual Disability

We seek to provide a patient centred network which will meet the needs of those with rare congenital malformation and intellectual disability syndromes, both diagnosed and undiagnosed and will provide an infrastructure for diagnosis, evidence-based management and collection of patient data. The network will add value to existing services, disseminate best practice guidelines to optimise patient care, facilitate training and capacity building in field, inform the work of service commissioners and enhance research and development of future therapies.
A Proposed ERN For Rare Congenital Malformations and Intellectual Disability

We seek to provide a patient centred network which will meet the needs of those with rare congenital malformation and intellectual disability syndromes, both diagnosed and undiagnosed and will provide an infrastructure for diagnosis, evidence-based management and collection of patient data. The network will add value to existing services, disseminate best practice guidelines to optimise patient care, facilitate training and capacity building in field, inform the work of service commissioners and enhance research and development of future therapies.

ITHACA

Intellectual disability TeleHealth And Congenital Anomalies
Proposed ERN Structure
ITHACA; RARE CONGENITAL MALFORMATIONS AND INTELLECTUAL DISABILITY

Endorsement process is on track in:

- 1. UK
- 2. Italy (may be more)
- 3. France (June 17th)
- 4. Netherlands
- 5. Portugal
- 6. Belgium
- 7. Lithuania
- 8. Cyprus
- 9. Romania
- 10. Czech Republic
- 11. Sweden
- 12. Finland
- 13. Hungary
- 14. German (still in progress)
Patient Involvement

An overarching feature of our network
Initiated from the beginning
Patient/lay group workshop convened
EURORDIS election of e-PAG representatives
Teleconferences for patient/lay groups
Inclusion in workpackage development
Suggestions for how we can work together
Workpackages

Management and Coordination
Dissemination
Evaluation

Expert patient care
TeleHealth and Diagnosis
Patient Registries
Research
Teaching and Training

Required to identify goals, objectives and deliverables, methods to deliver and the timeline for this
Challenges

• Determining membership
• Setting up a network with no initial resources
• Communication and IT
• Large amount of EU paperwork (3 docs/HCP plus additional 4)
• Avoiding overlap with other networks and initiatives
• Choosing SMART deliverables which are achievable within our likely budget
• Writing a competitive application – not all proposed networks will be funded
The Positives So Far

• Even before a network is approved, parents and professionals have spent many hours of time thinking how they can improve the lives of those with rare disease

• We have learned a huge amount from patients about what they want and what they can contribute

• We have learned a great deal from each other
Current Position

• 38 possible members from 15 member states

• Good patient Involvement

• Central review of HCP Self Assessments

• 5 year plan completed

• IT plans ongoing

• Challenge of submission process ahead!

• UK 2
• FRANCE 8
• NETHERLANDS 4-5
• ITALY 7-9
• GERMANY 2-3
• BELGIUM 3
• ROMANIA 1-2
• HUNGARY 1
• CZECH REPUBLIC 1
• PORTUGAL 1
• LITHUANIA 1
• CYPRUS 1
• SWEDEN 1
• FINLAND 1
• (SPAIN)