## Value of Treatment for Brain Disorders research project “Case studies on Rare Diseases and Mental Disorders”

8 June 2021 – Virtual Synthesis Meeting PROVISIONAL AGENDA

Meeting Afternoon Session (13.00 – 17.00)

<table>
<thead>
<tr>
<th>Time</th>
<th>Session Details</th>
</tr>
</thead>
<tbody>
<tr>
<td>13.00 – 13.05</td>
<td><strong>Welcome and objectives of the Synthesis Meeting</strong> by the Chair, Ms. Joke Jaarsma, EFNA President</td>
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<tr>
<td>13.05 – 13.10</td>
<td><strong>Teaser/video - What is the Value of Treatment for Brain Disorders project and why is the study so timely?</strong></td>
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<tr>
<td>13.10 – 13.15</td>
<td><strong>Opening keynote on the Value of Treatment for Brain Disorders and the need for more research</strong> by Prof. Monica Di Luca, EBC President</td>
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<td>13.15 – 13.20</td>
<td><strong>Opening keynote on health systems resilience and today’s challenges: the impact of Covid-19 on health services provision for brain disorders</strong> by Dr Hans Kluge, Director, WHO European Office – to be confirmed</td>
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</tbody>
</table>
| 13.20 – 13.30 | **Introduction: Addressing the burden of neurological diseases** by Prof. Claudio Bassetti, EAN President  
**Introduction and research framework: Early intervention, bridging the gaps and achieving seamless, coordinated care** by Prof. Wolfgang Oertel, EBC Vice President |
| 13.30 – 14.00 | **Synthesis – presentation of the results: case studies on rare diseases**  
The care pathway analysis and the economic modelling conclusions  
- **The case study on Ataxias** by Prof. Paola Giunti and Prof. Steve Morris  
- **The case study on Dystonia** by Prof. Maja Relja and Prof. Stipe Oreskovic |
### SESSION 1: Case studies and the Care Pathway Analysis

- **The case study on Phenylketonuria** by Prof. Gregory Pastores and Prof. Steve Morris

### 14.00 – 14.05

**Comments: towards an overarching perspective on the care pathway analysis and health economics study for rare diseases** by Prof. Giuseppe Turchetti, Professor of Economics and Management of Innovation in Healthcare, Scuola Superiore Sant’Anna Pisa, Italy

### 14.05 – 14.30

**Panel discussion moderated by EBC**
- Dr Yann Le Cam, Chief Executive Officer, Eurordis – to be confirmed
- Mr Enrique Terol, EC DG Santé – to be confirmed
- Prof. Holm Grassner, ERN-RND – to be confirmed
- Prof. Francjan J van Sproonsen, MetabERN – to be confirmed
- Dr Suzanne Gaunt, Chief Executive Officer, ICHOM – to be confirmed

### 14.30 – 15.00

**Q&A: open discussion with patients and patient associations**
Discussion moderated by EFNA

### 15.00 – 15.15

**BREAK**

### SESSION 2: Preliminary Results – Case studies on Mental Disorders

- **Introduction: Addressing the burden of mental disorders** by Prof. Philip Gorwood, EPA President
- **Introduction and research framework: Early intervention, bridging the gaps and achieving continuity of care** by Prof. Patrice Boyer, EBC Vice President

### 15.15 – 15.25

**Synthesis – presentation of preliminary results: case studies on mental disorders**

- **The care pathway analysis and the economic modelling**
  - **The case study on Anorexia Nervosa** by Prof. Janet Treasure and Prof. Eva Bonin
  - **The case study on Autism Spectrum Disorder** by Prof. Celso Arango and Prof. Martin Knapp
  - **The case study on Major Depressive Disorder** by Prof. Allan Young and Prof. Paul McCrone

### 15.55 – 16.00

**Comments: towards an overarching perspective on the care pathway analysis and health economics study for mental disorders** by Prof. Judit Simon, Professor of Health Economics, Medical University of Vienna, Austria

### 16.00 – 16.30

**Q&A: open discussion with patients and patient associations**
Discussion moderated by GAMIAN - Europe

### 16.30 – 16.50

**Overall remarks moderated by EBC**
- Ms Sandra Gallina, Director-General – Directorate-General Health and Food Safety (SANTE) - to be confirmed
- Prof. Jose Miguel Caldas de Almeida, Lisbon Institute of Global Mental Health, CHRC/Nova Medical School – to be confirmed

### CLOSING

- **Final words and way forward** by the Chair, Ms. Joke Jaarsma, EFNA President