



**2<sup>nd</sup> ROUND 2018-2021**  
**BRIDGING THE GAPS &**  
**ACHIEVING SEAMLESS,**  
**COORDINATED CARE**

EBC RESEARCH PROJECT - THE **VALUE OF TREATMENT** FOR BRAIN DISORDERS IN EUROPE

## 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)

<b>OPENING SESSION</b>	
<b>13.00 – 13.05</b>	<b>Welcome and objectives of the Synthesis Meeting</b> by the Chair, Ms. Joke Jaarsma, EFNA President
<b>13.05 – 13.10</b>	<b>Teaser/video - What is the Value of Treatment for Brain Disorders project and why is the study so timely?</b>
<b>13.10 – 13.15</b>	<b>Opening keynote on the Value of Treatment for Brain Disorders and the need for more research</b> by Prof. Monica Di Luca, EBC President
<b>13.15 – 13.20</b>	<b>Opening keynote on health systems resilience and today's challenges: the impact of Covid-19 on health services provision for brain disorders</b> by Dr Hans Kluge, Director, WHO European Office – to be confirmed
<b>SESSION 1: Results – Case studies on Rare Diseases</b>	
<b>13.20 – 13.30</b>	<b>Introduction: Addressing the burden of neurological diseases</b> by Prof. Claudio Bassetti, EAN President <b>Introduction and research framework: Early intervention, bridging the gaps and achieving seamless, coordinated care</b> by Prof. Wolfgang Oertel, EBC Vice President
<b>13.30 – 14.00</b>	<b>Synthesis – presentation of the results: case studies on rare diseases</b> <b>The care pathway analysis and the economic modelling conclusions</b> <ul style="list-style-type: none"><li>- <b>The case study on Ataxias</b> by Prof. Paola Giunti and Prof. Steve Morris</li><li>- <b>The case study on Dystonia</b> by Prof. Maja Relja and Prof. Stipe Oreskovic</li></ul>

	<ul style="list-style-type: none"> <li>- <b>The case study on Phenylketonuria</b> by Prof. Gregory Pastores and Prof. Steve Morris</li> </ul>
14.00 – 14.05	<b>Comments: towards an overarching perspective on the care pathway analysis and health economics study for rare diseases</b> by Prof. Giuseppe Turchetti, Professor of Economics and Management of Innovation in Healthcare, Scuola Superiore Sant'Anna Pisa, Italy
14.05 – 14.30	<b>Panel discussion moderated</b> by EBC <ul style="list-style-type: none"> <li>- Dr Yann Le Cam, Chief Executive Officer, Eurordis – to be confirmed</li> <li>- Mr Enrique Terol, EC DG Santé – to be confirmed</li> <li>- Prof. Holm Grassner, ERN-RND – to be confirmed</li> <li>- Prof. Francjan J van Spronsen, MetabERN – to be confirmed</li> <li>- Dr Suzanne Gaunt, Chief Executive Officer, ICHOM – to be confirmed</li> </ul>
14.30 – 15.00	<b>Q&amp;A: open discussion with patients and patient associations</b> <b>Discussion moderated</b> by EFNA
15.00 – 15.15	<b>BREAK</b>
<b>SESSION 2: Preliminary Results – Case studies on Mental Disorders</b>	
15.15 – 15.25	<b>Introduction: Addressing the burden of mental disorders</b> by Prof. Philip Gorwood, EPA President <b>Introduction and research framework: Early intervention, bridging the gaps and achieving continuity of care</b> by Prof. Patrice Boyer, EBC Vice President
15.25 – 15.55	<b>Synthesis – presentation of preliminary results: case studies on mental disorders</b> <b>The care pathway analysis and the economic modelling</b> <ul style="list-style-type: none"> <li>- <b>The case study on Anorexia Nervosa</b> by Prof. Janet Treasure and Prof. Eva Bonin</li> <li>- <b>The case study on Autism Spectrum Disorder</b> by Prof. Celso Arango and Prof. Martin Knapp</li> <li>- <b>The case study on Major Depressive Disorder</b> by Prof. Allan Young and Prof. Paul McCrone</li> </ul>
15.55– 16.00	<b>Comments: towards an overarching perspective on the care pathway analysis and health economics study for mental disorders</b> by Prof. Judit Simon, Professor of Health Economics, Medical University of Vienna, Austria
16.00 – 16.30	<b>Q&amp;A: open discussion with patients and patient associations</b> <b>Discussion moderated</b> by GAMIAN - Europe
16.30 – 16.50	<b>Overall remarks moderated</b> by EBC <ul style="list-style-type: none"> <li>- Ms Sandra Gallina, Director-General – Directorate-General Health and Food Safety (SANTE) - to be confirmed</li> <li>- Prof. Jose Miguel Caldas de Almeida, Lisbon Institute of Global Mental Health, CHRC/Nova Medical School – to be confirmed</li> </ul>
<b>CLOSING</b>	
16.50 – 17.00	<b>Final words and way forward</b> by the Chair, Ms. Joke Jaarsma, EFNA President