



29th Workshop of the EURORDIS Round Table of Companies

How to teach an old medicine new tricks The importance of repurposing medicines for patients

Wednesday, 19 February 2020 (09.00 to 17.30)
The Crowne Plaza – Le Palace, Brussels, Belgium

PROGRAMME

Morning Session Co-Chairs: Serge Braun, Scientific Director, AFM-Téléthon Lydie Meheus, Managing Director, Anticancer Fund	
09.00 - 09.20	Welcome introduction, setting the scene & goals for the day Yann Le Cam, Chief Executive Officer, EURORDIS-Rare Diseases Europe
09.20 – 09.40	EU initiatives on timely access to innovative medicines Helen Lee, Administrator, Health and Food Safety Directorate-General, European Commission
Stakeholders' interests for repurposed medicines: why do we need them and why is it difficult to obtain?	
09.50 – 10.05	Marc Doods , Senior Orphan Drug Pharmacist, Leuven University Hospitals
10.05 – 10.20	Ciska Verbaander , PhD Student, Anticancer Fund
10.20 – 10.35	Karine Proulx , Drug and Discovery Alliance Manager, Healx
10.35 – 11.00	<i>Discussion</i>
11.00 – 11.30	<i>Coffee break</i>
The absence of a regulatory framework is one of the difficulties. How can the STAMP initiative help and how does it work?	
11.30 - 11.50	The STAMP proposal: the framework, how it works, pilots, Repurposing Observatory Group César Hernández García, Head of the Department of Medicines for Human Use, Spanish Agency of Medicines and Medical Products (AEMPS)
11.55 – 13.00	Facilitated panel discussion and Q&A from audience Panellist representatives: Christelle Bouygues, Regulatory Affairs Officer, European Medicines Agency Sini Eskola, Director, Team Leader Regulatory, Drug Development and Manufacturing, EFPIA Beate Stepniewska, Deputy Director General & Head of Regulatory Affairs, Medicines for Europe Lakshminarayan Ranganath, Professor, Royal Liverpool University Hospital, AKU Society Trustee
13.00 – 14.00	<i>Lunch</i>

Afternoon Session Co-Chairs: Pablo Lapunzina, Scientific Director, CIBERER Elena Beltrami, Technology Transfer Manager, Fondazione Telethon	
How can we support academics and non-profits in repurposing medicines? Incentives, intelligence, funding, etc.	
14.00 – 14.15	EU funded research for drug re-purposing Ferenc Marofka, Policy Officer, Health Research & Innovation Directorate-General, European Commission
14.15 – 14.30	Barbara Goodman , President & Chief Operating Officer, Cures Within Reach
14.30 – 15.00	Q&A from audience
15.00 – 15.20	<i>Coffee break</i>
What do you think of this initiative? Initial reactions and discussion	
15.20 – 16.20	<p>3 simultaneous Breakout Sessions, all sessions will address:</p> <ul style="list-style-type: none"> ✓ Initial reactions: given current legal framework, does scientific advice respond to industry's questions when deciding whether or not to repurpose a medicine? ✓ Are relations between champions, regulators and industry clear or are there aspects that require simplifying or alternatives? ✓ Pricing of repurposed medicines: how to keep prices reasonable - reactions/concerns/questions from industry and other stakeholders?
	<p><u>Breakout session 1</u></p> <ul style="list-style-type: none"> • Moderator: François Houÿez, Treatment Information and Access Director, Health Policy Advisor, EURORDIS-Rare Diseases Europe • Rapporteur: Russell Wheeler, Co-founder, LHON Society
	<p><u>Breakout session 2</u></p> <ul style="list-style-type: none"> • Moderator: Simone Boselli, Public Affairs Director, EURORDIS-Rare Diseases Europe • Rapporteur: Vesna Aleksovska, Chair & BoD of the International Gaucher Alliance, BoD of Macedonia National Alliance, Chairman of the association of citizens for rare diseases
	<p><u>Breakout Session 3</u></p> <ul style="list-style-type: none"> • Moderator: Elizabeth Vroom, Founder & President of the Duchenne Parent Project Netherlands • Rapporteur: Leonardo Scapozza, Pharmaceutical Biochemistry/Chemistry, School of Pharmaceutical Sciences, University of Geneva
International Initiatives	
16.30 – 17.00	IRDiRC Task Force on repurposing and initiatives at NCATS/NIH Noel Southall, Leader, Division of Pre-Clinical Innovation, Informatics National Center for Advancing Translational Sciences, National Institutes of Health
17.00 – 17.20	Q&A from audience
17.20 – 17.25	The importance for industry to repurpose medicines for patients Wendy Eler, Vice President, Patient Experience/STAR & Patient Advocacy, Alexion
17.25 – 17.30	Concluding remarks and next steps François Houÿez, Treatment Information and Access Director, Health Policy Advisor, EURORDIS-Rare Diseases Europe
17.30	<i>Meeting ends</i>