EUCOPE
European Confederation of Pharmaceutical Entrepreneurs AISBL

15 May 2019
11.00 – 16.00 CET

EUCOPE offices
Rue Marie de Bourgogne, 58
1000 Brussels

EUCOPE OMP WORKING GROUP

Meeting agenda

	SESSION TOPIC	SPEAKER
1	**Welcome / Introduction / Meeting agenda and objectives**	Chairs
2	**Community Advisory Boards (CABs)** • Presentation of the CAB concept • Feedback and lessons learned on a company experience • Presentation of EUCOPE's draft position • Group discussion	Rob Camp, EURORDIS Flaminia Macchia, Vertex Philipp Galwitz, Admedicum
3	**EUCOPE Study on the OMP Regulation** • Project objectives, timelines (refresher) • Presentation of the initial findings • Next steps	Martina Garau, OHE Secretariat
4	**EUCOPE's initial reflections towards improved access to orphan medicinal products in Europe** • Presentation of EUCOPE's draft recommendations in response to the EURORDIS 2018 Paper on "Breaking the Access Deadlock to Leave No One Behind"	Tbd
5	**Increased collaboration in rare disease Research and Development** • Presentation of recommendations for a path for Research & Industry to collaborate in Rare Disease data collection • EUCOPE's position on European Reference Networks • Update on the ERNs' response on ERN-industry interactions	George Reynolds, RareUrn Wills Hughes-Wilson, Mereo (tbc)
6	**National updates** • An update on the German Parliament discussions on the Draft Law for More Safety in the Supply of Medicinal Products (GSAV) • Presentation of the 2019 Working Plan for the Spanish Network of Agencies of Health Technology Assessment and National Health System Coverage (RedETS), including activities on the cost-effectiveness of new-born screening for different pathologies	Alexander Natz, EUCOPE Max Brosa, Oblikue (tbc)
7	**EMA discussion paper on the use of patient registries for regulatory purposes** • Presentation of EUCOPE's comments	Maren von Fritschen, EUCOPE

EUCOPE

European Confederation of
Pharmaceutical Entrepreneurs AISBL

SESSION TOPIC		SPEAKER
8	**Rare Diseases Research Challenges – an update**	Secretariat
9	**A.O.B / Meeting conclusion**	Chairs