

PROGRAMME AT A GLANCE

Thursday 10 May 2018

09:30 - 16:00	ePAG representatives meeting
09:30-13:00	RDI General Assembly (members only)
14:00-16:00	RDI Annual meeting (open to members and non-members of RDI)
16:30-18:30	EURORDIS General Assembly (members only)
19:00-21:00	Patient Groups Welcome Reception

Friday 11 May 2018

09:00-09:45	Opening Session
09:45-10:15	Coffee Break
10:15-12:30	Plenary Session
12:30-13:30	Lunch
13:00-14:00	Poster Sessions & Shire Satellite symposium

Themes	1/ Structuring the Research and Diagnostic Landscape	2/ Breakthrough medicines on the horizon	3/ The Digital Patient	4/ Quality of Life: Making what matters, matter	5/ Economical Perspectives in Rare Diseases	6/ Global Rare Equity: Are we there yet?
14:00-15:30	Session 0101 Transformations in diagnostics: how research and European Reference Networks are re-shaping the diagnosis landscape	Session 0201 Breakthrough products and priority medicines	Session 0301 Everything is technically possible	Session 0401 Quality of life - what really matters to patients & how to measure it	Session 0501 Economic impact of rare diseases on patients, families and society	Session 0601 How can we leverage global policies and global agencies to explicitly support rare diseases recognising diversity and ensuring equity?
15:30-16:30	Poster Sessions					
16:30-18:00	Session 0102 Research: from an idea to the real world	Session 0202 Current EU cooperation on Health Technology Assessment: EUnetHTA	Session 0302 Societal, legal and ethical framework	Session 0402 How can quality of life contribute to decision making?	Session 0502 Economic dynamics of therapy development for rare diseases	Session 0602 What global opportunities do we unlock when all people living with a rare disease have access to a timely accurate diagnosis and optimised care?
18:00-19:00	Reception (for all participants)					

Saturday, 12 May 2018

Themes	1/ Structuring the Research and Diagnostic Landscape	2/ Breakthrough medicines on the horizon	3/ The Digital Patient	4/ Quality of Life: Making what matters, matter	5/ Economical Perspectives in Rare Diseases	6/ Global Rare Equity: Are we there yet?
09:00-10:30	Session 0103 Innovative funding partnerships: challenges and opportunities	Session 0203 The Future of Health Technology Assessment Cooperation	Session 0303 EC Digital Single Market Strategy	Session 0403 Disability: unveiling the invisible double-burden of rare diseases	Session 0503 A paradigm shift in value frameworks for access	Session 0603 IRDIRC next horizon 2027: Research from vision to the real world
10:30-11:00	Coffee Break & Poster Sessions					
11:00-12:30	Session 0104 Patient involvement: Is it enough to be an 'expert by experience?'	Session 0204 Orphan medicinal products in the pipeline: what can we see coming and disappearing?	Session 0304 European Reference Networks as a future model of healthcare	Session 0404 Integrated care: bringing together health & social care, two sides of the same patient	Session 0504 Enhancing patient access to care: new approaches to pricing and funding	Session 0604 Building the Rare Disease knowledge and information eco-system through better connections
12:30-13:30	Lunch					
13:30-14:30	"Soap box" Plenary Session featuring Flora Giorgio, Head of Sector Health Technology Assessment, DG SANTE B4, European Commission.					
14:30-16:00	Session 0105 Genome editing debate: Are we heading towards a world without rare diseases?	Session 0205 Preparing the contribution of patients in regulatory / Health Technology Assessment procedures	Session 0305 Patients and the digital revolution	Session 0405 From best practices to next practices: building a collaborative vision	Session 0505 A look into the future - how to ensure sustainability access to rare diseases care in 2030?	Session 0605 What are our key enablers to bring a vision for equity and optimised care globally to people living with a rare disease locally?
16:15-17:00	Closing Plenary Session					
17:00-17:30	Farewell Coffee					