





Academic Medical Center
University of Amsterdam

European Fabry Working Group meeting, Amsterdam, Tuesday November 14, 2017

Location: Amsterdam, AMC, Ziedses des Planteszaal

Symposium to discuss new developments and findings from the GGG study (optimal use of medicines program) conducted by **Maarten Arends** in collaboration with AMC, Royal Free Hospital, Universitätsklinikum Wurzburg and CFDI.

Financial support: ZonMW, The Netherlands Organisation for Health Research and Development.

	session 1: GGG study outcomes	Chair: Patrick Deegan
	EFWG group, patient reps, regulators, payers, pharma	
09.45	Welcome	Carla Hollak
09.50	Outline of the GGG-study and criteria for phenotyping	Carla Hollak
10.15	Natural History of Fabry disease	Derralynn Hughes
10.45	Renal disease in relation to phenotype	Christoph Wanner
11.15	Coffee break	
11.35	Cardiac risk factors for disease progression	Alexander Hirsch
11.55	Quality of life in Fabry disease	Simon Korver
12.15	Comparison of agalsidase alfa versus beta and timing of	Maarten Arends
	treatment	
13.00	Lunch	
	session 2: new treatments	Chair: Christoph Wanner
	EFWG group, patient reps, regulators, payers, pharma	
13.45	New treatments in Fabry disease: for whom?	Patrick Deegan
14.15	New treatments: gene therapy	Michael West
14.45	Interplay between mitochondria and lysosomes: relevance	Simon Heales
	for Fabry disease	
15.15	Tea break	
	session 3: ways forward for EFWG	Chair: Michael West
	EFWG and patient reps only	
15.30	Ways forward: spin-off of the GGG study	Carla Hollak
	- expanding the registry	
	- phenotype/genotype database	
	- revision consensus criteria start-stop	
16.00	General discussion	
16.30	End of meeting	