



Fabry International Network

7th Fabry Expert Meeting

21st / 22nd – 26th May 2019

Barcelona

The primary aim of the Fabry International Network is to facilitate collaboration between patient organisations around the world to support those affected by Fabry disease

Draft Full Weekend Programme

Tuesday 21st May

Schedule	Programme	Participants
12.00 – 17.00	FIN Board Arrival - optional	X 8
18.30 – 21.00	FIN Board Dinner	X 8

Wednesday 22nd May

Schedule	Programme	Participants
10.00	Coffee on arrival	X 8
10.00 - 12.30	FIN Board Meeting	X 8
12.30 – 13.00	Lunch (FIN Board only)	X 8
13.00 – 14.00	Avrobio & FIN	
14.00 - 15.30	Chiesi & Protalix & FIN	
15.30 – 15.45	Break	X 8
15.45 – 17.15	Sanofi & FIN	2 Sanofi – FIN Board
17.15 – 18.15	Open Timeslot - TBD	
18.30 – 21.00	FIN Board Dinner	X 8

Thursday 23rd May

Schedule	Programme	Participants
09.30 – 11.00	Amicus & FIN	
11.00 – 11.15	Break	X 8
11.15 – 12.15	Sangamo & FIN	
12.15 – 13.15	Moderna & FIN	
13.15 – 14.00	Lunch FIN Board only	X 8
14.00 – 15.30	Idorsia & FIN	
15.30 - 17.00	Shire & FIN	
17.00 – 17.45	GreenOvation & FIN	
17.45 – 18.45	Freeline & FIN	
19.00	Dinner	X 8

Friday 24th May

Schedule	Programme	Participants
09.00-17.00	<i>Members & speakers: Registration & Welcome</i>	50
09.30–11.00	Members Workshop – <i>Understanding the psychological needs of Fabry Disease</i> Moderators – <i>Dr Nadia Ali & Anna Meriluoto</i>	X 8 – 10
	Members Workshop – <i>Symptom management/sharing experiences</i> <i>Moderators - Mary Pavlou & Lut De Baere</i>	X 8 – 10
	Members Workshop – <i>Let's talk Fabry Men</i> <i>Moderators- Jack Johnson & Martynas Davidonis</i>	X ???
	Members Workshop – <i>Let's talk Fabry Women</i> <i>Moderators- Anne Grimsbo & Erica Van De Mheen</i>	X ???
11.00–11.30	Tea & Coffee	X 30
11.30 - 13.00	Members Workshop – <i>Understanding the psychological needs of Fabry Disease</i> Moderators - <i>Dr Nadia Ali & Anna Meriluoto</i>	X 8 – 10
	Members Workshop – <i>Symptom management/sharing experiences</i> <i>Moderators - Mary Pavlou & Lut De Baere</i>	X 8 – 10
	Members Workshop – <i>Let's talk Fabry Men</i> <i>Moderators- Jack Johnson & Martynas Davidonis</i>	X ???
	Members Workshop – <i>Let's talk Fabry women</i> <i>Moderators – Anne Grimsbo & Erica Van De Mheen</i>	X ???
13.00 - 14.00	Lunch Sandwich/Buffer	X 30
14.00 - 15.30	Members Workshop – <i>Understanding the psychological needs of Fabry Disease</i> Moderators - <i>Dr Nadia Ali & Anna Meriluoto</i>	X 8 – 10
	Members Workshop – <i>Symptom management/sharing experiences</i> <i>Moderators - Mary Pavlou & Lut De Baere</i>	X 8 – 10
	Members Workshop – <i>Let's talk Fabry Men</i> <i>Moderators- Jack Johnson & Martynas Davidonis</i>	X ???
	Members Workshop – <i>Let's talk Fabry women</i> <i>Moderators- Anne Grimsbo & Erica Van De Mheen</i>	X ???
15.30 - 16.00	Tea & Coffee	X 30
16.00 - 17.00	AGM - Members only	X 40
19.00	Dinner	All X 75 -80

Saturday 25th May

Schedule	Programme	Participants
08.45– 09.00	Welcome - <i>Lut de Baere</i>	X 77 -80
09.00 – 09.30	The Challenges of a Fabry Patient organisation Spain - <i>Jordi Cruz</i>	X 77 -80
09.30 – 10.00	Living with Fabry Disease (in Spain) - <i>Francisco Albiol</i>	X 77 -80
10.00 – 10.30	Fabry Disease in Spain - <i>Dr Alberto Ortiz</i>	X 77 -80
10.30 – 11.00	Break	X 77 -80
11.00 – 11.30	Fabry in Women - <i>Prof Dominique Germain</i>	X 77 -80
11.30 – 12.00	Planning a family: what are my options? - <i>Alison Wilson</i>	X 77 -80
12.00 – 12.30	Japanese survey – <i>Ikuko Kaku</i>	X 77 -80
12.30 – 13.30	Lunch	X 77 -80
13.30 – 14.00	Study of Fabry Fog / The Psychosocial impact of Fabry - <i>Dr Nadia Ali</i>	X 77 -80
14.00 – 14.30	Kidney / Nephrology – <i>Dr Alberto Ortiz</i>	X 77 -80
14.30 - 15.00	Update Fabry Poland	X 77 -80
15.00 – 15.30	Break	X 77 -80
15.30 – 16.30	The Spanish Multidisciplinary Guide on Fabry Disease - <i>Dr. Ignacio Marin-Leon</i>	X 77 -80
16.30 – 17.00	Pain - <i>Dr Jorge Hernandez-Vara</i>	X 77 -80
17.00 - 17.15	Wrap Up – <i>FIN Board TBD</i>	X 77 -80
17.15 – 19.00	Break	X 77 -80
19.00 - Late	Dinner	X 80-85

Sunday 26th May

Schedule	Programme	Participants
09.30 – 10.00	New and emerging treatments – <i>Dr Guillem Pintos</i>	X 77 -80
10.00 – 11.00	Cardiac disease in Fabry Patients – <i>Dr Javier Limeres-Freire - TBC</i>	X 77 -80
11.00 – 12.30	Evaluation, Farewell & Check out	X 77 -80
12.30 – 13.30	FIN Board Meeting	X 8

Free Airport shuttle from Airport

Fabry International Network
E: info@fabrynetwork.org
Charity Registration Number 04080030: Chamber of Commerce Drenthe The Netherlands
www.fabrynetwork.org