



# Fabry International Network

## 7th Fabry Expert Meeting

**21<sup>st</sup> / 22<sup>nd</sup> – 26<sup>th</sup> 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

## Friday 24<sup>th</sup> May

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

## Saturday 25<sup>th</sup> May

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

## Sunday 26<sup>th</sup> May

Schedule	Programme	Participants
09.30 – 10.00	New and emerging treatments – <i>Dr Guillem Pintos</i>	<i>All</i>
10.00 – 11.00	Cardiac disease in Fabry Patients – <i>Dr Javier Limeres-Freire</i>	<i>All</i>
11.00 – 12.30	Evaluation, Farewell and check-out	<i>All</i>
<b>12.30 – 13.30</b>	<b>FIN Board Meeting</b>	<b><i>Board members</i></b>

Free Airport shuttle from Airport

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