



National Workshop on Patients' Rights and Rare Diseases

Date: Thursday 29th February 2024

Time: 08.30 am – 03.30pm

Venue: Mediterranean Conference Centre, Valletta, Malta

Agenda

08.30 – 09.00 am	Registration and welcome coffee Location: Sacra Infermeria Hall
	<u>Opening Session</u> Location: Vassalli Hall
09.00 – 09.10 am	Opening speech by the <i>Hon Mr Jo Etienne Abela</i> Minister for Health and Active Aging
09.10 – 09.20 am	Welcome speech by <i>Dr Giulio Gallo</i> (European Commission representative) and <i>Ms Sandra Gallina</i> (Director-General – Directorate-General Health and Food Safety (SANTE), European Commission)
	<u>Plenary Session 1: Cross-border Healthcare</u> Location: Vassalli Hall
	<i><u>Chair Dr Anthony Gatt</u></i>
09.20 – 09.40 am	Cross border care under the Patient's Rights directive: impact and opportunities <i>Dr Ewout van Ginneken</i>
09.40 – 09.50 am	Malta and Cross-Border healthcare <i>Dr Anthony Gatt</i>
09.50 – 10.00 am	Leading together for the mutual benefit of all - MyHealth@EU and Cross Border eHealth Services in Malta <i>Dr Stefan Buttigieg</i>
10.00 – 10.15 am	Q&A

10.15 - 10.45 am - Coffee break

Location: Sacra Infermeria Hall

Plenary Session 2: European Reference Networks and Rare Diseases

Location: Vassalli Hall

Chair Dr James Clark

10.45 – 11.00 am	The European Reference Networks – Raising the bar for patients' with rare diseases and their healthcare providers across Europe <i>Dr James Clark</i>
11.00 – 11.10 am	European Reference Network in rare diseases, common challenges and successes <i>Dr Antonio González-Meneses</i>
11.10 – 11.20 am	ERN registries - ERKReg as an example for rare kidney diseases <i>Dr Stefanie Haberle</i>
11.20 – 11.40 am	Experiencing a rare disease
11.40 – 11.55 am	Q&A

12.00 – 01.00 pm - Lunch & coffee

Location: Sacra Infermeria Hall

Session 3: Parallel sessions

01.00 – 02.00 pm	<i>Break out rooms and parallel sessions:</i> <ul style="list-style-type: none">● Parallel session 1: Patients' Rights and Rare Diseases Location: Vassalli Hall Panellists: <i>Dr Giulio Gallo, Ms Gertrude Buttigieg, Ms Rhoda Garland, Mr Oliver Scicluna</i>● Parallel session 2: ERNs and Rare Diseases Registries Location: David Bruce Hall Panellists: <i>Dr Antonio González-Meneses, Mr Stefano Vettorazzi, Dr Stefanie Haberle, Dr Miriam Azzopardi, Dr Jeanette Scerri</i>
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- **Parallel session 3: Cross-border healthcare and eHealth**

Location: Michel' Angelo Grima Hall

Panellists: *Dr Ewout van Ginneken, Dr Anthony Gatt,
Dr Stefan Buttigieg*

Testimonial: *Mr Jan Quintus Engelenburg*

02.15 – 03.00 pm

Conclusions from the parallel sessions

Location: Vassalli Hall

Chair: Dr Cristina Micallef

Summaries from the parallel sessions followed by a panel discussion

03.00 – 03.30 pm

Workshop Closure

Dr Giulio Gallo and Mr Walter Busuttill