

# FRIDAY 28 APRIL 2023

# The path of patient advocacy: past, present and future

## Agenda

| 9:00-9:30   | Registration   |  |  |
|-------------|--|--|--|
| 9:30-10:00  | Opening address  |  |  |
|             | Marco Greco, EPF President   |  |  |
|             | Back to the future address: A view from a young patient leader   |  |  |
|             | Marleen Sorensen, EPF Youth Group  |  |  |
|             | Keynote intervention   |  |  |
|             | Maya Matthews, Acting Director for Digital Health, EU4Health and Health Systems, European Commission       |  |  |
| 10:00-10:45 | Plenary 1. Looking back – perspectives from diverse stakeholders: Did EPF deliver on its founding promise? |  |  |
|             | Panel discussion with EPF members and stakeholders, including:   |  |  |
|             | Anders Olauson, honorary EPF president   |  |  |
|             | Maria Navarro, former EPF board member   |  |  |
|             | Robert Madelin, former Director General for Health in the European Commission                              |  |  |
|             | Nicola Bedlington, former EPF Secretary General  |  |  |
|             | Moderated by <b>Brian West</b> , EPF Vice-president  |  |  |
| 10:45-11:15 | Coffee break   |  |  |





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Looking back: What can be learned from EPF's first 20 years? What worked well - and what didn't? What could be improved?

#### Parallel Workshop 1: Developing effective policy and advocacy campaigns

Moderated by Claudia Louati, incoming Head of Policy, EPF

Discussants:

Juan Garcia Burgos, EMA

Michele Calabro, Euregha

Rapporteur: Susanne Melin, Bosch Foundation

#### Parallel Workshop 2: Building capacity in the patient community

Moderated by **Elena Balestra**, Head of EPF Membership, Capacity Building and Governance

**Discussants:** 

Radu Costin Ganescu, COPAC, Romanian Coalition of Chronic Disease Patients Anastasia Semaan, EPF Youth Group

Rapporteur: Veronica Rubio, Association of European Coeliac Societies (AOECS)

#### Parallel Workshop 3: Shaping the stakeholder and research environment

Moderated by Valentina Strammiello, Director of Programmes, EPF

Discussants:

Paul Robinson, Patient Engagement Lead, Europe, MSD

Nicholas Brooke, PFMD / The Synergist

Rapporteur: Dimitrios Athanasiou, WDO

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| 12:15-12:45             | Plenary 2. Plenary session discussing workshop outcomes with the rapporteurs from each group $% \left( 1\right) =\left( 1\right) +\left( 1\right$ |  |
| 12:45-14:00             | Lunch  |  |
| 14:00-14:30             | Plenary 3. Introducing the draft Patient Organisations' Manifesto  |  |
|                         | Robert Hejzák, National Association of Patient Organisations, Czechia  |  |





14:30-15:45

Looking forward: What ambition for the patient movement in the next 10 years? Where do we want to get to and how do we get there?

### Parallel Workshop 4: Developing effective policy and advocacy campaigns

Moderated by Anca Toma, EPF Executive Director

Discussants:

Nathalie Moll, EFPIA Executive Director

Yannis Natsis, ESIP Director

Rapporteur: Milka Sokolovic, EPHA

#### Parallel Workshop 5: Building capacity in the patient community

Moderated by Ilaria Leggeri, EIT Health

Discussants:

Konstantina Boumaki, EPF Youth Group

Annabel Seebohm, COCIR

Rapporteur: Maria Dutarte, EUPATI

#### Parallel Workshop 6: Shaping the stakeholder and research environment

Moderated by Anke Peggy Holtorf, HTAi

Discussants:

Anne-Charlotte Fauvel, EATRIS

Laura Savini, European Haemophilia Consortium

Rapporteur: Neil Johnson, Global Heart Hub

| 15:45-16:15 | Coffee break   |
|-------------|--|
| 16:15-16:45 | Plenary 4. Plenary session discussing workshop outcomes with the rapporteurs from each group |
| 16:45-17:15 | Closing session. Presentation of the patient organisations' manifesto                        |
|             | Konstantina Boumaki, EPF Youth Group   |
|             | Closing address  |
|             | Marco Greco, EPF President   |
| 18:00       | Networking cocktail  |
| 19:00       | Anniversary Dinner   |



