

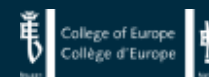
# Rare Diseases: Think Sustainable, Think Digital, Think Patient!

*Norbert Couespel, Chair, Future-Proofing Health Systems Committee,  
European Health Parliament (7th edition)*

**2nd International Conference on Rare Diseases: Greek Chapter. 2 March 2022**

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# Rare Diseases

*One reality, one challenge, one opportunity*

- A **reality**: 300 million patients across the world, including 30 million in Europe
- A **challenge**: Rarity, and its impacts on innovation and patients' access to care
- An **opportunity**: European collaboration to bring together resources and expertise

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# The European Health Parliament (EHP)

*Who we are*

- A **pan-European movement**: connecting and empowering 60 selected young health leaders from across Europe to rethink EU health policies
- A **belief**: that Europe's fresh ideas for health must come from the young European leaders who influence the policies that will ultimately concern their generation as they age
- **Key themes** for EHP7: Recover, Reinvest, Reinvent: Creating a resilient European Health Union
  - Think Sustainable
  - Think Digital
  - Think Patient

Find out more: [healthparliament.eu](https://healthparliament.eu)

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# The European Health Parliament (EHP)

*What we do*

- Providing the **next generation of European leaders** with the connections, knowledge and platform they need to build a healthier and more innovative Europe
- Developing for **policy recommendations** addressing today's most pressing European health issues, picked in cooperation with the European Commission:
  - Digital Health Transition and Governance
  - **Future-Proofing Health Systems**
  - Preventive and Self-Care
  - Sustainable Health Systems
  - Well-being of healthcare workers
- **Engaging with stakeholders and decision-makers** to build wide consensus within the healthcare community and advocate for change

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# The European Health Parliament (EHP)

*What we do: Rare Diseases*

- **European health data cooperation (EHP6 & EHP4)**
  - **Strengthen European Reference Networks**
    - Increasing financing of ERNs within the EU4Health Programme
    - Simplifying budget access procedures to allow deployment of research and improve citizens' access to treatment
    - Developing new ERNs for complex conditions
  - **Fund training for expert data stewards**
    - Advising stakeholders in each Member State on how to manage data according to FAIR standards and preparing data for secondary use

*Endorsements including:*

- *Former European Health Commissioner Vytenis Andriukaitis*
- *Former European Parliament MEP Antonio Tajani*
- *Former WHO representative to the EU Roberto Bertolini*
- *6 MEPs and former MEPs*
- *COCIR Director-General Nicole Denjoy*

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# The European Health Parliament (EHP)

*What we do: Rare Diseases*













- **Tackling cancer in Europe: Fighting inequalities (EHP5):**
  - **Focusing research on rare and paediatric cancers**
    - Initiating an EU reflection for innovative and adaptative clinical trial design for paediatric cancers
    - Updating regulatory requirements for drugs targeting rare and paediatrics cancers for better post-launch surveillance to make sure that the EU incentive schemes allow effective patients access in all member states

*Endorsements including:*

- *Association of European Cancer Leagues (ECL)*
- *EFPIA Oncology Platform*
- *European Cancer Patient Coalition (ECPC)*

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# EHP7: Future-Proofing Health Systems

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# EHP7: Future-Proofing Health Systems

*What we work on: Rare Diseases*

- **Our vision:** Upholding health a social good and a right for all people and communities
- **Our ongoing axis of work:**
  - Making rare disease patient rights a reality
  - Putting rare disease patient needs at the centre when defining unmet medical needs
  - Harmonising implementation of European regulations at national level
  - Fostering effective collaboration on evidence generation and resource spending for easier, faster and fairer access to treatment
- **Our messages:**
  - Think Sustainable, Think Digital, Think Patient!
  - Engage with us! ([norbert.couespel@healthparliament.eu](mailto:norbert.couespel@healthparliament.eu))

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**Thank you for your  
attention!**