

THE 10<sup>th</sup> EUROPEAN CONFERENCE ON  
RARE DISEASES & ORPHAN PRODUCTS



ONLINE on 14-15 May **2020**

THE **JOURNEY** OF LIVING WITH  
a **RARE DISEASE** in

**2 0 3 0**

## JOIN US AT THE LARGEST PATIENT-LED RARE DISEASE EVENT TAKING PLACE IN EUROPE

Leading, inspiring and engaging all rare disease  
community stakeholders to take action



**Hundreds of  
attendees**

including patient advocates,  
healthcare professionals,  
healthcare industry,  
academics, regulators, payers  
and policy makers



**days**

14-15 May 2020  
ONLINE



**Worldwide  
attendance**



**# ECRD2020**



**Over 100**

expert chairs, speakers  
and panellists

### PROGRAMME COMMITTEE CO-CHAIRS



**Prof. Milan Macek**

Professor of Medical and  
Molecular Genetics, Motol  
University Hospital and  
Charles University Prague,  
Czech Republic



**Maria Montefusco**

President, Rare  
Diseases Sweden



**Violeta Stoyanova-Beninska**

Chair, Committee of Orphan  
Medical Products, European  
Medicines Agency

Organised by



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With the support of



Co-funded by  
the Health Programme  
of the European Union

## LEARN - NETWORK - INSPIRE

- › **Engage** with a large range of stakeholders in the rare disease field that are affected by the policies you put in place
- › **Hear** from people living with a rare disease first-hand about their needs, experience and expectations and get insight into how patient associations can contribute to policy-making
- › **Exchange** views on the most recent and promising developments in the field of rare diseases, such as new therapies and technologies, use of big data, or current and upcoming research
- › **Share** your work and vision on upcoming policy proposals affecting innovation, health care organisation, access to medicine and the ethical, legal, technological and economic issues that surround them
- › **Take the pulse** of national policies on rare diseases and learn about best practices that can inspire your work in your country
- › **Explore** rare disease-related opportunities and challenges and how your policies can help shaping healthcare systems that foster patient-centered approaches and scientific innovation
- › **Get involved** in collective efforts to shape policies that will change the policy landscape in the next decade
- › **Help** shaping a better future for people living with a rare disease
- › **Learn about** progress and the future of European Reference Networks (ERNs) for rare diseases – how they can enhance health outcomes for patients, their integration into national health systems and future plans for their financing

## LANGUAGES

Simultaneous interpretation and live streaming of the Opening and Plenary sessions on 14 May 2020 will be available in:

ENGLISH | FRENCH | GERMAN

For more information, please visit [www.rare-diseases.eu](http://www.rare-diseases.eu)

