THE 10th EUROPEAN CONFERENCE ON RARE DISEASES & ORPHAN PRODUCTS

ecrd

ONLINE on 14-15 May 2020

THE JOURNEY OF LIVING WITH a RARE DISEASE in 2030

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

2 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

EURORDIS RARE DISEASES EUROPE

Co-organised by

orphanet
Inserm

With the support of

AFMTÉLÉTHON INNOVER POUR GUÉRIR

Co-funded by the Health Programme of the European Union

LEARN – NETWORK – INSPIRE

› **Dialogue** with all of the stakeholders shaping your environment: patient advocates, policy makers, regulators, member state representatives, academia, researchers, clinicians, HTA evaluators, payer bodies and industry colleagues

› **Learn about** the future of diagnosis: its new hopes, promises and challenges

› **Explore** the implications of emerging pricing, reimbursement and access trends

› **Hear from** patients first-hand about their needs and experiences

› **Co-create** the policies and services of the future to support measurable and improved health outcomes for people living with a rare disease

› **Exchange views** on technological developments that are changing the rare disease landscape

› **Debate** the ethical, legal and social implications of far-reaching topics such as data sharing, gene editing and access to new therapies

› **Get insight** into how to work collaboratively with patient organisations

› **Explore** the opportunities and challenges of care provision and the potential to shape healthcare systems that are sensitive to patients and open to scientific innovation

› **Learn** about the important progress made to advocate for rare diseases as a health and human rights priority at the United Nations and international agencies

› **Be inspired** by concrete practices that healthcare companies implement to enable a patient-centric approach to therapeutic development

› **Learn about** progress and the future of European Reference Networks (ERNs) for rare diseases - how they can contribute to improve health outcomes for patients, their integration into national health systems, and future plans for their financing

› **See** the full picture of how different elements are coming together at global, regional and country level to support orphan medicinal products discovery, development and access

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**