

THE 10th EUROPEAN CONFERENCE ON
RARE DISEASES & ORPHAN PRODUCTS



ONLINE on 14-15 May 2020

THE JOURNEY OF LIVING WITH
a RARE DISEASE in

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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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the Health Programme
of the European Union

LEARN - NETWORK - INSPIRE

› **What does the future look like for people living with a rare disease?**

Join us and co-create the policies and services of the future. What is important for you? Help us identify measurable and improved health outcomes for people living with a rare disease.

› **How do people living with a rare disease benefit from developments in science and technology?**

Exchange views on the evolutions that are changing the rare disease landscape. What are the ethical, legal and social implications in areas such as data sharing, digital innovations, scientific breakthroughs, etc.?

› **How do I get better access to healthcare?**

Explore with us the challenges we meet in accessing healthcare. How can you play a role in transforming care provision in the future?

› **What does the future of diagnosis look like?**

Learn about hopes, promises and challenges of future diagnostics

› **What is going on to improve the development of rare disease therapies?**

Discover recent innovations in clinical research and regulatory solutions. What are the roadblocks, challenges and opportunities in developing therapies that match the needs of people living with a rare disease?

› **Holistic care – when do we finally get it?**

Learn more about growing efforts to advocate for organised and integrated social support and patient-centred care at the national level

› **Quicker access to the latest therapies – even for people living with a rare disease!**

Debate the challenges and solutions. How to ensure sustainability when developing therapies that are truly available to all people living with a rare disease.

› **What is going on at the policy level?**

Understand the processes behind the decisions made by regulators, policy makers and healthcare industry professionals impacting the rare disease community.

› **How can I contribute? Share your experiences!**

Share your inspiring and innovative strategies, services or projects. Join our open microphone plenary session or present your ideas as a poster and inspire others with your outstanding ideas.

› **Come and network with us!**

We offer special registration prices and fellowship programmes for Patient advocates. Attend the ECRD alongside 850+ other participants and build your capacity as rare disease advocate.

› **Stand out from the crowd!**

Make your voice heard as a thought leader in the rare disease community. Meet other advocates and stakeholders directly related to your work.

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

