

BLACKSWAN[®] FOUNDATION

SWISS FOUNDATION FOR RESEARCH ON ORPHAN DISEASES
SCHWEIZERISCHE STIFTUNG FÜR DIE FORSCHUNG SELTENER KRANKHEITEN
FONDATION SUISSE POUR LA RECHERCHE SUR LES MALADIES ORPHELINES
FONDAZIONE SVIZZERA PER LA RICERCA SULLE MALATTIE ORFANE

Closing remarks

Distinguished guests and participants I would like to thank you on behalf of the organizers and partners of the policy event. It is indeed my pleasure to make a few closing remarks and express gratitude to all those who made this event a reality.

- Today we achieved an important milestone, today we are no longer alone.
- Today we are not a silent minority anymore, today our voice was heard.
- Today we can finally focus on finding concrete solutions for people living with RD, today the right to health of millions of people starts to be respected!

There are few points that I would like to highlight following today's discussions as taking home messages:

1. The first take home message is that we have to recognise that the right to health of persons living with RD is often violated because of insufficient investments in health care services and research and because of inadequate access and coverage of expenses for the treatment for RD.

To guarantee the right to health of persons with RD, greater investments are required to address the absence of adequate market incentives for unmet health needs.

The insufficient attention paid by global institutions and actors to diseases of poverty and to neglected and RD lead to dangerous imbalances and inequalities, which carry a heavy price.

2. It was said that RD must be part of the 2030 Agenda for Sustainable Development adopted by the UN:

Innovation through research and health technologies is the key element to enlarge health coverage.

This means that investing in R&D and thinking about how to improve access for health products for RD is also a way to address many challenges of the future of healthcare for non-communicable diseases.

3. The importance of investing in innovation was underlined today as well in the UN High-Level Panel on Access to Medicines report, which stated that greater investments are required from governments to address unmet health needs such as in the case of RD

4. Collaboration, Sharing and Public Private Partnerships are the key factors. I like to remind it very often, in research, only collaborative project can lead in breakthrough inventions or treatments. For this reason, we create the RE(ACT) Initiative, a scientific network to facilitate the cooperation among the researchers.

And, this is true in all fields. Only a strong collaboration between governments, International institutions and the RD community can achieve our common goal:

treatments for millions even beyond the RD community!

5. Developing new treatments for RD is our goal but to ensure that nobody is left behind treatments must be also accessible.

Drugs for RD are often extremely expensive and not always reimbursed. This creates inequalities and discrimination, for this reason, policies should provide incentives for treatments discovery but also find ways of ensuring medicines are affordable and can reach patients all over the world.

As we had this fruitful discussion here in Geneva where the World Health Organization is based, I would like to close this day with an appeal to the World Health Assembly to consider discussing RD in one of its forthcoming meeting

Thank you so much to each one of you to pave the way of making RD a global health priority