

## SEMINARIO

# “Enfermedades frecuentes: Como avanzar al desarrollo de una política”

Viernes 30 de julio 2021  
9:00 horas | Vía zoom

In Chile, it is estimated that more than 1 million people have some rare disease, however, there is no National policy that addresses the challenges of these pathologies. The main gaps of our country lie in the need to raise awareness, generate data that allows quantify the patients, train doctors, encourage early diagnosis, provision of quality, integrated and networked services, advance in universal coverage, generate spaces for further development of research, but overall, generate policies for protection and social inclusion for rare disease patients.

## PROGRAM

### OPENING SESSION

- ▶ **Carolina Goic**, Senator of the Republic of Chile
- ▶ **Enrique Paris**, Minister of Health of Chile

### PRESENTATIONS

#### “National Health Strategy 2021-2030”

- ▶ **Johanna Acevedo**, Head of Health Planning Division at Ministry of Health of Chile

#### “Rare disease objectives prioritization”

- ▶ **Domenica Taruscio**, Director of the National Centre for Rare Diseases at the Italian National Institute of Health and ICORD President.

#### “¿How can impulse a rare disease policy?”

- ▶ **Alba Ancochea**, Patient Advocates Constituent Committee member in International rare diseases research consortium

### Questions and Answers

### WORKSHOP: OBJECTIVES PRIORIZATION FOR NATIONAL HEALTH STRATEGY 2021-2030 (10:00-12:00)

Closed workshop in which 6 focus groups of 8 people will be held, moderated by an expert in qualitative methodology to discuss and prioritize objectives and indicators to be incorporated into the National Health Strategy. From this process, a discussion report will be executed with the prioritized objectives to be delivered to the work table of the Ministry of Health of Chile in this matter.