

9, 11 and 13 of november

# International Congress on the Effects of COVID19 on People with Rare Diseases

· 12-15h (Buenos Aires time)  
· 16-19h (Barcelona time)



## Vaccines: What are they and how are they developed?

The COVID19 vaccine. The  
anti-vaccine movement and its  
impact on public health

Moderator: **Pablo Barvosa**

Pediatrician at Hospital Garrahan, former secretary  
of the group of rare diseases of the Argentine  
Society of Pediatrics



**Nov 9**  
16h (BCN) / 12h (Bs. As.)

### SPEAKERS

**Dr. Gonzalo Perez Marc**

Deputy Director of the  
Pediatrics Service of the  
Central Military Hospital and  
Director of the Study of the  
Vaccine against SARS-CoV-2  
of Pfizer

**Dr. Quique Bassat**

ICREA Research Professor,  
Director of the Malaria Program  
(ISGlobal). Pediatrician expert in  
infectious diseases (Hospital  
Sant Joan de Déu)

**Dr. Roberto Debbag**

Vice President of the Latin  
American Society of Pediatric  
Infectology

**Dr. Fernando Polack**

Pediatrician and Principal  
Investigator of Pfizer's Vaccine  
Project



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### SPEAKERS

**Carles Fàbrega Agulló**

Coordinator of Telemedicine  
Hospital Sant Joan de Déu  
Barcelona. President of the  
Iberian Society of Telemedicine  
and Telehealth (SITT)

**Luiz Ary Messina**

Since 2006, he has coordinated  
the RUTE University  
Telemedicine Network, under  
the direction of the RNP  
National Research and  
Teaching Network. President of  
the Brazilian Association of  
Telemedicine and Telehealth  
ABTms

**Begonya Nafria**

Share4Rare Coordinator and  
Patients engagement in  
research Coordinator

**Fernanda Ledesma**

Coordinator of Hospital  
Bioethics, Hospital Nacional  
de Pediatría J. P. Garrahan

**Dra. Celeste Savignano**

Coordinator of Telehealth and  
Distance Communication.  
Ministry of Health, Argentina

## Bioethics

Cases of good use of ICT in the  
prevention and management  
of comorbidity of the disease

Moderator: **Florencia Ugo**

Institutional Psychologist of the Coordination of  
Networks and Distance Communication, Hospital  
Garrahan



## How does COVID19 affect the child population?

Schooling in times of  
COVID19

Moderator: **Dr. Marcelo Andrade**

External Consultation Pediatrician - Consultant Level  
of the Sant Joan de Déu Hospital in Barcelona.  
Clinical manager of the Vincles Program with Primary  
Care. Former Head of the Outpatient Clinic of  
Garrahan Hospital and of the Garrahan Hospital  
Distance Communication Office



**Nov 9**  
18h (BCN) /  
14h (Bs. As.)

### SPEAKERS

**Ida Schwartz**

Head of the Medical Genetics  
Service of the Hospital de  
Clínicas de Porto Alegre -  
Universidade Federal do Rio  
Grande do Sul, Brazil

**Lina Bertrán**

Head of Education at UNICEF  
Bolivia

**Nacho Guadix Garcia**

Head of Education in Children's  
Rights and Campaigns of  
UNICEF Spain

**Irene Melamed**

Pediatrician and specialist in  
adolescence. Co-founder of  
the Adolescence Section of the  
Hospital Nacional General de  
Niños "Ricardo  
Gutiérrez". Professor and  
Senior Researcher in the  
Bioethics Program, FLACSO.  
Vice President of the Argentine  
Society for Comprehensive  
Adolescent Health.

**Sr. Jordi Cruz**

Director of MPS-Lisomales  
Spain

**Dra. Fernanda Hendges de**

**Bitencourt**

National Institute of Popular  
Medical Genetics - INAGEMP,  
Hospital de Clínicas de Porto  
Alegre

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**Nov 11**  
16h (BCN) / 12h (Bs. As.)

### SPEAKERS

**Jill Pollander**

Director of Patient Services at the National Organization for Rare  
Disorders (NORD)

**Clara Hervàs**

Public Affairs Manager, Rare Disease & Policy coordinator, NGO  
Committee for Rare Diseases

## Emotional support to affected people: the role of patient organizations and virtual communities

Information and  
disinformation: access to  
reliable sources of scientific  
content

Moderator: **Roberta Anido de Pena**

President of the Argentine Federation of rare  
diseases -FADEPOF



## Change of paradigm: care model focused on the patient and their environment from primary care to high complexity

The role of primary care at  
EPOF: My family doctor

Moderator: **Virginia Fano**

Pediatrician Chief Growth and Development Service.  
Coordinator of the interdisciplinary group Skeletal  
Dysplasias. Juan P Garrahan Hospital, Argentina



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### SPEAKERS

**Dr. Juan Llerena (Brasil)**

Geneticist Coordinator of the  
Center for Medical Genetics and  
Reference Center for Doenças  
Raras e Osteogênese  
Imperfeita Fernandes Figueira  
National Institute. Fundação  
Oswaldo Cruz Rio de Janeiro  
Brazil. National Plan and  
reference centers in EPOF

**Virginia Fano (Argentina)**

Pediatrician Chief of the Growth  
and Development Service.  
Coordinator of the  
interdisciplinary group Skeletal  
Dysplasias. Juan P Garrahan  
Hospital, Argentina.  
Cooperative Management in  
Uncommon Skeletal Diseases  
from infancy to the transition to  
Adult medicine

**David Peña (Mexico)**

President of the Project Make a  
Wish Mexico (PPuDM) and of  
the Mexican Federation of Rare  
Diseases (FEMEXER)

**Dr. Mariana Nastri (Argentina)**

Pediatrician Specialist in Health  
Economics and Management.  
Low Risk Sector Coordinator  
(Ambulatory Area). Head of the  
Programmed Care Area a/c  
Hospital de Pediatría J.P.  
Garrahan, Argentina. Garrahan  
Model of care and changes in  
times of Covid

**Dr. Francesc Palau (Barcelona)**

Director of the Genetic and  
Molecular Medicine Service and  
the Pediatric Institute for Rare  
Diseases (IPER) of the Sant Joan  
de Déu Hospital, director of the  
Sant Joan de Déu Research  
Institute. Professor at the  
University of Barcelona and  
research professor at the  
Higher Council for Scientific  
Research (CSIC). National Plan  
and reference centers in EPOF

## Social problems of COVID19 in the EPOF collective in Argentina

Moderator: **Florencia Braga**

General Director of Projects of ALAPA



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### SPEAKERS

**Dra. María José Martínez**

**Cáceres**  
Pediatrician, Head of clinic at  
the Doctor's office for Complex  
Chronic Conditions, Garrahan  
Hospital

**María José Nacci**

Doctor in Social Sciences from  
the University of Buenos Aires.  
Dean of the Faculty of Social  
and Human Sciences-UK.  
Teacher, researcher and writer

**Dr. Nicolás Atamañuk**

Head of the Multidisciplinary  
Pulmonary Hypertension Group,  
Juan A. Fernández Hospital,  
Buenos Aires. Head of Heart  
Failure and Pulmonary  
Hypertension and Heart  
Transplant Coordinator, Austral  
University Hospital. Professor at  
the Faculty of Medicine,  
University of Buenos Aires

**Melody Escudero Amada**

Patient with Charcot-Marie-  
Tooth disease

**Nicolás Kreplach**

Vice Minister of Health of the  
province of Buenos Aires

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## The challenge of patients without diagnosis: challenges and needs

Moderator: **Florencia Braga**

General Director of Projects of ALAPA



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### SPEAKERS

**Dr. Pablo Barvosa**

Pediatrician at Hospital  
Garrahan, former secretary of  
the group of rare diseases of  
the Argentine Society of  
Pediatrics

**Dr. Marcelo Kauffman**

Neurologist, Dr. José María  
Ramos Mejía Hospital in  
Buenos Aires.

**Dr. Marcelo Andrade**

External Consultation  
Pediatrician - Consultant Level  
of the Sant Joan de Déu  
Hospital in Barcelona. Clinical  
manager of the Vincles  
Program with Primary Care.  
Former Head of the Outpatient  
Clinic of Garrahan Hospital and  
of the Garrahan Hospital  
Distance Communication Office



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### SPEAKERS

**Dr. Roberto Mato**

Pediatrician, Specialist in  
Adolescent Care. Head of the  
Adolescence Unit Clinic of the  
Garrahan Hospital, Buenos  
Aires

**Dra. Esther Via Virgili**

Adjunct Psychiatrist and post-  
doctoral researcher, Total  
Hospitalization Unit of  
Psychiatry, Department of  
Child-Adolescent Psychiatry  
and Clinical Psychology, Sant  
Joan de Déu Hospital,  
Barcelona. Research Institute  
Sant Joan de Déu Hospital,  
Barcelona

**Dra M. Alejandra Bordato**

Head of the Child and  
Adolescent Psychiatry and  
Psychology, Head of Clinic of  
the Mental Health Service of the  
Hospital de Pediatría Hospital  
Garrahan

**Dr. Xavier Estrada**

Associate Psychiatrist, Total  
Hospitalization Unit of  
Psychiatry, Department of  
Child-Adolescent Psychiatry  
and Clinical Psychology,  
Hospital Sant Joan de Déu,  
Barcelona

**Luca Sangiorgi**

MD, PhD Coordinator, European  
Reference Network Bone  
Rare Diseases ERN BOND  
Medical Genetic Department,  
Istituto Ortopedico Rizzoli - Italy

## Recovery and sequels of COVID19

Mental health and EPOF in times  
of COVID19

Moderator: **Dra. Patricia Elmeaury**

Pediatrician, Medical Advisor at the Hospital de  
Pediatría Garrahan and Deputy Secretary of the  
EPOF group of the Argentine Society of Pediatrics



## ERNs from European Commission



**Nov 13**  
18h (BCN) / 14h (Bs. As.)

**Dr. Enrique Terol**

European Reference Networks and Digital Health, DG  
SANTE. European Commission

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Share4Rare

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More information:

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