

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)

Begonya Nafria

Share4Rare Coordinator

Dra. Celeste Savignano

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

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

Fernanda Ledesma

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

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
Bolívia

Nacho Guadix García

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-Lisosomales
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
Research Council for Scientific
Research (CSIC). National Plan
and reference centers in EPOF

Social problems of COVID19 in the EPOF collective in Argentina

Moderator: **Flor Braga**

General Director of Projects of ALAPA



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SPEAKERS

Maria José Nacci

Dean of the Faculty of Social
and Human Sciences at John
F. Kennedy University

Melody Escudero Amada

Patient with Charcot-Marie-
Tooth disease

Nicolás Kreplach

Vice Minister of Health of the
province of Buenos Aires

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

**Dra. María José Martínez
Cáceres**

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



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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

The challenge of patients without diagnosis: challenges and needs

Moderator: **Flor Braga**

General Director of Projects of ALAPA



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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 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

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



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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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