

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



Nov 9
17h (BCN) / 13h (Bs. As.)

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 Bolivia

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 Hedges 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



Nov 11
17h (BCN) / 13h (Bs. As.)

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 Osvaldo 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



Nov 11
18h (BCN) / 14h (Bs. As.)

SPEAKERS

María 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

Social problems of COVID19 in the EPOF collective in Argentina

Moderator: **Flor Braga**

General Director of Projects of ALAPA



Access the conferences for Wednesday



The challenge of patients without diagnosis: challenges and needs

Moderator: **Flor Braga**

General Director of Projects of ALAPA



Nov 13
16h (BCN) / 12h (Bs. As.)

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



Nov 13
17h (BCN) / 13h (Bs. As.)

SPEAKERS

Dr. Roberto Mato

Pediatrician, Specialist in Adolescent Care. Head of the Adolscence 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

Dr. M. Alejandra Bordato
Specialist in Child and Adolescent Psychiatry and Psychology, Head of Clinic 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

Access the conferences for Friday



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Share4Rare

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More information:

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