

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
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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

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.

Lina Bertrán
Head of Education at UNICEF Bolivia

Sr. Jordi Cruz
Director of MPS-Lisosomales Spain

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

Dra. Fernanda Hendges de Bitencourt
National Institute of Popular Medical Genetics - INAGEMP, Hospital de Clínicas de Porto Alegre

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



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



Nov 11
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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

Social problems of COVID19 in the EPOF collective in Argentina

Moderator: Florencia Braga

General Director of Projects of ALAPA



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

SPEAKERS

Dra. María José Martínez Cáceres
Pediatrician, Head of clinic at the Doctor's office for Complex Chronic Conditions, Garrahan Hospital

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

Maria 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

Melody Escudero Amada
Patient with Charcot-Marie-Tooth disease

Nicolás Kreplach
Vice Minister of Health of the province of Buenos Aires

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 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

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



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

SPEAKERS

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

Dra M. Alejandra Bordato
Specialist in Child and Adolescent Psychiatry and Psychology, Head of Clinic of the Mental Health Service of the Hospital de Pediatría Hospital Garrahan

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. 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 Elmeaudy

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.)

SPEAKERS

Dr. Enrique Terol
European Reference Networks and Digital Health, DG SANTE. European Commission



Sign up!



More information: info@share4rare.org

