



THURSDAY, 29 OCTOBER

15:00 h: Welcome and Opening remarks.

Juan Carrión: President of the Iberoamerican Alliance for Rare, Orphan and Uncommon Diseases.

15:50 h: INAUGURAL SPEECH

WHO CGNRD LATAM Global Network of Rare Disease Centers. The Role of the Patients and Framework in Iberoamerica. Matthew Bolz-Johnson, Healthcare and ERN Advisor EURORDIS. **Flaminia Macchia,** Rare Diseases International Management and **Clara Hervas,** Rare Diseases International Policy Coordinator.

16:25 h ROUNDTABLE 1: Presenter and Moderator: Inés Castellano. Vice-President of ALIBER

THE IMPORTANCE OF A COMMON DEFINITION OF RARE, ORPHAN AND UNCOMMON DISEASES.

16:30 – 16:55 h: Ana Rath: Director of Orphanet

17:00 - 17:15 h: Nomenclature and Definition of Rare Diseases in Peru. Karla Ruíz de Castilla: President of Esperantra, Peru and member of the ALIBER Board of Directors

17:15 - 17:30 h: Nomenclature and Definition of Rare Diseases in Ecuador, Eliecer Quispe: President of Fundación Ecuatoriana De Pacientes Con Enfermedades De Depósito Lisosomal (Ecuadorian Foundation for Patients with Lysosomal Storage Diseases) and member of the ALIBER Board of Directors

17:30 – 17:45 h: Nomenclature and Definition of Rare Diseases in Uruguay. Martha Giménez: President of Federación Uruguaya de Instituciones de Discapacidad-FUDI (Uruguay Federation of Disability-related Institutions) and member of the ALIBER Board of Directors

17:45 – 18:10 h: Definition and Prevalence in Latin American Countries – A Differential Comparative. Estrella Guerrero Solana. Project Manager at ALIBER

18:10 – 18:25 h: Q&A session and group participation



18:25 h: ROUNDTABLE 2: Presenter and Moderator: Regina García Próspero: Vice-President of ALIBER

NATIONAL AND INTERNATIONAL ASSOCIATIVE NETWORK BEST PRACTICES

18:30 h – 18:50 h. Path of care and support for access to education for students with Rare Diseases. A work of the municipal technical table for orphan diseases of Santiago de Cali in collaboration with Patient Organisations. Solanyi Mosquera, Social affairs Technical Health Area, Secretary of Health of Cali.

18:50 – 19:00 h National and International Associative Network Best Practices through the Iberoamerican Group of Respiratory Care in Neuromuscular Diseases. Dr. Francisco Prado (Chile), Associate professor of paediatrics at University of Chile and member of the Iberoamerican Group of Respiratory Care in Neuromuscular Diseases.

19:05 – 19:20 h Research Project Development. ENSERio LATAM Study. Alba Ancochea. Advocate at ALIBER

19:20 – 19:30 h Q&A session and group participation.

19:30 h ROUNDTABLE 3: Presenter and Moderator: Luz Victoria Salazar: Vice-President ALIBER

EMPOWERMENT AND LEARNING FOR PATIENTS AND PATIENT-ADVOCACY ORGANIZATIONS.

19:35 – 19:55 h Informed Patients, Agents of Change. Eva María Ruiz de Castilla, President and Executive Director of LAPA (Latin American Patient Academy).

20:00 – 20:15 h Associative Movement and Visibility. Viviana Pérez, President of Asociación Turner de Uruguay (Uruguay Turner Association) and **Dra. Carla Scanniello** President of La Asociación de Enfermedades Raras de Retina Stargardt Uruguay (The Association for Retina Stargardt Rare Diseases in Uruguay).

20:15 - 20:30 h Q&A session and group participation

20:30 – 21:30 h Workshop: Digital Innovation and Leadership for Patient Organizations in Latin America. Migdalia Denis. Master Life Coach. Expert patient.

21:30 h End of session



FRIDAY, 30 OCTOBER

15:00 h ROUNDTABLE 4: Presenter and Moderator: Alba Ancochea: Director, FEDER

NATIONAL POLICIES AND ACTION PLANS FOR RARE, ORPHAN AND UNCOMMON DISEASES.

15:05 - 15:25 h Action Plan Regarding Rare Diseases APEC. An Opportunity to Implement Policies for Rare Diseases in a Collaborative Framework in Asia-Pacific. Eric Obscherning: Secretary of APEC RD Action Plan and **Matthew Belgard** Chair of the APEC Rare Disease Network

15:30 - 15:50 h The Importance of the Economy in Public Discourse about Uncommon Diseases. Antonio Miguel Bañón Hernandez. Professor at Universidad de Almería.

15:55 - 16:15 h RDI, Actions with the WHO to Guarantee Universal Health Coverage. Durhane Wong. President of RDI

16:20- 16:35 h Civil Organizations' Advocacy for Rare Diseases in the Mexican State's Actions. Minister Tanya Patricia Palacios Tejeda: Genes Latin America

16:35 – 16:50 h Strategic Politics to Bring Attention to and Include People with Rare or Uncommon Diseases, Case study, Jalisco, Mexico. Minister Rodolfo Carlos Torres Gutiérrez. Director of Inclusion for People with Disabilities. Subsecretary of Human Rights | Secretary General of the Government

16:55 - 17:10 h 10 Years of Rare Disease Law in Colombia – Achievements, Challenges and Opportunities. Ms. Luz Victoria Salazar. President of ACOPEL

17:10 – 17:20 h Q&A session and group participation

17:25 H ROUNDTABLE 5: Presenter and Moderator: Enrique Pastor, Professor at Universidad de Murcia.

ORPHAN AND RARE DISEASE MEDICATIONS, A GLOBAL CHALLENGE

17:30 - 17:50 h 20 years of European regulation of orphan drugs. Jorge Capapey: President of the Asociación Española de Laboratorios de Medicamentos Huérfanos y Ultrahuérfanos (AELMHU) (Spanish Association of Laboratories for Orphan and Ultraorphan Drugs)

17:55 - 18:15 h Buying Expensive Medication in Latin American Countries. Dr. Julio Daniel Mazzoleni Insfran: Ministry of Health in Paraguay.

18:20 – 18:40 h Accessing Orphan Medications – Needs, Difficulties and Processes. Manuel Pérez. President of the Pharmaceutical Society of Seville (Spain) and President of **Fundación MEHUER** (Fundación Medicamentos Huérfanos y Enfermedades Raras) (Foundation for Rare Diseases and Orphan Medications).

18:40 – 18:50 h Q&A session and group participation

18:55 h ROUNDTABLE 6: Presenter and Moderator: Jesús Navarro: Vice-president of ALIBER

EARLY DIAGNOSIS IN RARE, ORPHAN AND UNCOMMON DISEASES

19:00 - 19:20 h Challenges in Neonatal Detection of Rare Diseases in Latin American. Dr. Marta Ascurra, Neonatal Detection Program Director for the Paraguay Ministry of Public Health and Social Wellbeing.

19:20 - 19:40 h Neonatal Screening in México. Xochitl N. Mendoza Morales: President of the Asociación Mexicana de Amigos Metabólicos A.C (Mexican Association of Metabolic Friends A.C.)

19:40 – 19:50 h Q&A session and group participation

20:00 h ROUNDTABLE 7: Presenter and Moderator: Antonio G. Armas. Director of two radio programs, Enfermedades Raras (Rare Diseases) and Investigadores por el mundo, (Researachers around the World) on radio Libertad FM.

SOCIAL, EDUCATIONAL AND PSYCHOLOGICAL ASPECTS OF RARE DISEASES.

20:00 – 20:15 h: Meaning and Significance of Inclusion for Patients with Orphan Diseases in Five Education Institutions. María Fernanda García, Fundación Cronicare

20:15 - 20:30 h: Educational Intervention in the Classroom with Children with Rare or Undiagnosed Diseases. Pedro Tudela. Head of Educational Programs at DGenes.

20:30 – 20:45 h: “Rights and Responsibilities of Informal Caretakers in Times of Health Emergencies.” Griselda Rodríguez Ruiz. Social worker specialized in rare diseases. (Mexico).

20:45 – 21:00 h: Book Launch: Para que las Enfermedades Huérfanas dejen de estar huérfanas en Colombia (What it Takes for Orphan Diseases to Stop Being Orphans in Colombia), Dr Germán Escobar, Ministry of Health Chief of Staff

21:00 h: Q&A session and group participation and end of session.



SATURDAY, 31 OCTOBER

15:30 h: ROUNDTABLE 8: Presenter and Moderator: Fide Mirón. Member of the FEDER Board of Directors

COVID 19 AND RARE DISEASES

15:35 - 15:50 h: Share4Rare International Registry of COVID-19 and Uncommon Diseases. Dr. Marcelo Andrade San Joan de Deu hospital, Barcelona and Dr. Pablo Barvosa, Argentina.

15:50 - 16:05 h: Rare Barometer Voices in Latin American Survey Results. Estrella Guerrero. Project Manager at ALIBER.

16:05 - 16:20 h: "Socio-Sanitary Systems Post COVID-19 and a Call to Action from the OSC to Prioritise National Uncommon Disease Plans" Luciana Escati Peñalosa. Executive Director of FADEPOF, Argentina.

16:20 - 16:35 h: Current State of Prioritised Health Care for Patients with Rare, Orphan and Uncommon Diseases in Ecuador. Maritza Cárdenas Peña. Representative for Fundación FEPEL DASHA

16:35 - 16:50 h: Protection of Rights in Uruguay. How Work Continued at the University Despite COVID, to Benefit Patients of Rare, Orphan and Uncommon Diseases. Dr. Juan Ceretta, Professor at Universidad de la República

16:50 – 17:00 h: Q&A session and group participation.

17:10 ROUNDTABLE 9: Presenter and Moderator: Alicia María Males: Management ALIBER

TREATMENT AND RARE, ORPHAN AND UNCOMMON DISEASES

17:10 – 17:30 h: The Challenge of Advanced Therapy Product Regulation in LATAM (LMI). Augusto Rojas Monterrey Institute of Technology and Higher Education, México

17:30 – 17:45 h Investigación internacional y ER. Manuel Posada de la Paz, MD, PhD Director, Institute of Rare Diseases Research (IIER) IRDIRC Funders Constituent Committee.

17:45 – 18:00 h: New Approaches for Transplants Not Related to Rare Disease Treatment. Dr. Juan Antonio Flores Jiménez. BE THE MATCH Transplantologist, Haematologist, Internal Medicine.

18:05 – 18:20 h: Be The Match®, Mexico's Bone Marrow Donor Registry. Sergio Medrano Murillo. Managing Director of Be the Match Mexico

18:20 - 18:35 h: Multidisciplinary Approach in Spinal Atrophy Treatment. Gloria Giménez, Kinesthesiologist and Physical Therapist at Hospital de Clínicas, School of Medicinal Science, Universidad Nacional de Asunción. Paraguay.

18:35 - 18:50 h: Cornelia de Lange Syndrome and its advances in Latin America. Dr. Feliciano Ramos Fuentes, Geneticist and paediatrician, President of the world scientific committee of Cdl's Federation, Director of a renowned Centre for Cornelia de Lange Syndrome patients, in the Hospital de Zaragoza.

This English translation has been possible thanks to the PerMondo project: Free translation of website and documents for non-profit organisations. A project managed by Mondo Agit. Translator: Leslie Hoffman



18:50 h: Q&A session and group participation.

19:00 h: CLOSING ACTS

- **Conclusions**
- **Good-byes and gratefulness.**





ORGANIZING COMMITTEE:

President:

Mr. Juan Carrión Tudela

President of ALIBER, President of FEDER and of FEDER Foundation (Spain)

Members:

Ms. Inés Castellanos

Vice-President of ALIBER

Mr. Jesús Navarro

Vice-President of ALIBER and President of OMER (Mexico)

Ms. Regina García

Vice-President of ALIBER and President of Instituto Vidas Raras (Rare Lives Institute) (Brazil)

Ms. Luz Victoria Salazar

Vice-President of ALIBER and President of ACOPEL (Colombia)

Ms Marta Giménez

Secretary of ALIBER and President of FUDI (Uruguay)

Mr. Eliecer Quispe

Treasurer of ALIBER and President of FEPEL DASHA (Ecuador)

Ms. Luisa Gabriela Acosta.

Member of ALIBER and President of AC Humberto Da Silva (Venezuela)

Ms. Deolinda Acosta

Member of ALIBER and President of AE y EA (Paraguay)

Ms. Myryam Estivil

Member of ALIBER and President of Fundación de Pacientes de Enfer. Lisosomales (Foundation for Patients with Lysosomal Diseases) (Chile)

Ms. María Delfina Tay

Member of ALIBER and President of PROCRECE (Guatemala)

Ms. Karla Ruiz.

Member of ALIBER and President of Esperantra (Perú)

Ms. Alba Ancochea Díaz

Psychologist. Head of Advocacy at ALIBER. Director of FEDER and its Foundation.

Ms. Alicia Males

Social worker and Head of Administration at ALIBER

Ms. Estrella Guerrero Solana. Social worker and Project manager at ALIBER.