ICBD 2023

Accelerating Action for Birth Defects and Disabilities: Surveillance, Prevention, Screening, Management and Family-Centered Care

PROGRAM & ABSTRACT BOOK

ICBD 2023 Hosted By

ESCUELA DE MEDICINA
FACULTAD DE MEDICINA

Our Sponsors
## Program at a Glance

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<th>WED</th>
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<tr>
<td><strong>8:00</strong></td>
<td>REGISTRATION 8:00-17:00</td>
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<tr>
<td><strong>8:30</strong></td>
<td><strong>WELCOME</strong></td>
<td><strong>PLENARY SESSION 4:</strong> (90 min) Newborn Screening for Metabolic and Structural Health Conditions</td>
<td>Simultaneous Symposia 6: (90 min) S16 Technology Application in BD Surveillance S17 Reduce CHD Burden in the Americas S18 Program Development for BD &amp; Rare Diseases Monitoring &amp; Care Intervention</td>
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<td><strong>9:00</strong></td>
<td><strong>PLENARY SESSION 1:</strong> (75 min) Partnerships and Programs for Accelerating Action for Birth Defects and Disabilities</td>
<td><strong>PLENARY SESSION 5:</strong> (60 min) Eliminating Violence, Stigma and Discrimination Against Persons with Birth Defects and Disabilities</td>
<td>Networking and Coffee Break</td>
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<td><strong>9:30</strong></td>
<td>Pre-Conference Workshop: Skills Building for Birth Defects Surveillance and Data Utilization (8:30-14:00)</td>
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<td><strong>10:00</strong></td>
<td><strong>PLENARY SESSION 2:</strong> (60 min) Improving Equitable Access: Integrating into Health System Services for Screening, Diagnosis and Management of BD</td>
<td><strong>PLENARY SESSION 5:</strong> (60 min) Eliminating Violence, Stigma and Discrimination Against Persons with Birth Defects and Disabilities</td>
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<td><strong>10:30</strong></td>
<td>Poster Session 1 (Posters 1 – 42), Networking and Coffee Break</td>
<td>Poster Session 2 (Posters 43 – 84), Networking and Coffee Break</td>
<td><strong>PLENARY SESSION 6:</strong> (60 min) The Voice of the Community &amp; Parent Organizations</td>
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<tr>
<td><strong>11:00</strong></td>
<td>Simultaneous Symposia 1: (90 min) S1 Global Burden of BD S2 Medical Genetics &amp; Genomics Literacy for Prevention of BD &amp; Disabilities S3 Care, Support, and Care Giver Experiences</td>
<td>Simultaneous Symposia 3: (90 min) S7 Quality &amp; Capacity Building for BD Surveillance: S8 Screening, Genetics, and Rare Diseases S9 What Drives Success in Pediatric Cardiac Care</td>
<td>CLOSING CEREMONY AND DEPARTURE</td>
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<td>14:00</td>
<td>REGISTRATION 14:00-16:30</td>
<td>PLENARY SESSION 3: (90 min) Addressing Micronutrient Deficiencies through Fortification and Supplementation for the Prevention of Adverse Birth Outcomes and Birth Defects</td>
<td>Simultaneous Symposia 4: S10 Understanding BD Risk Factors S11 Surveillance of BD in Latin America and the Caribbean S12 Health Systems in LMICs for Management of OFC</td>
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<td>Poster Session 2 (Posters 43 – 84), Networking and Coffee Break</td>
<td>15:00</td>
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<td>16:00</td>
<td>OPENING CEREMONY 16:30-18:30</td>
<td>Simultaneous Symposia 2: S4 Prevention Strategies &amp; Knowledge about Intervention S5 Mobilizing Children for Life: Improving Access to Clubfoot Care for Newborns in LMICs S6 Surveillance of BD in LMICs</td>
<td>Simultaneous Symposia 5: S13 BD Screening, Surveillance, and Treatment S14 CHD: Prevention, Diagnosis, and Management S15 Reversing Destiny: Role of Surgical Care in Birth Defects</td>
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<td>17:00</td>
<td>Opening Ceremony 16:30-18:30</td>
<td>Keynote Address: Anshu Banerjee, MD, PHD</td>
<td>Free Evening</td>
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<td>18:00</td>
<td>Cocktail Reception 18:30-20:00</td>
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<td>19:00</td>
<td>ICBD 2023 CONFERENCE DINNER 19:00</td>
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Location of Meeting Rooms

Welcome Cocktail
Plaza Gacitua

Grand Ballroom
G Room

DEF Room

ABC Room

Santiago Marriott Hotel
Avda. Presidente Kennedy 5741
Las Condes, Santiago - Chile

Lunchroom
Café Med

Poster Panels
64 to 71
14 to 21

Poster Panels
56 to 63
22 to 29

Foyer

Operation Smile

Pre Conference Room
Sierra Nevada

Information about Santiago
Learn more about Santiago, transportation, city tours, museums and other city information.
## Program in Detail

### WED | 1 March

<table>
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<th>TIME</th>
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<tr>
<td>08:30 - 14:00</td>
<td>PRE-CONFERENCE: WORKSHOP (Sierra Nevada)</td>
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Skills Building for Birth Defects Surveillance: Focus on Recognition, Description, and Coding  
Organized by ICBDSR, CDC, and WHO

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<td>10:00 - 11:00</td>
<td>REGISTRATION (Grand Ballroom with Simultaneous Translation)</td>
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Opening Remarks from Host University, Chile Ministry of Health, Sponsoring Agencies  
Family Representatives  
Keynote Address: Birth Defects in the Developing World, Integrating Screening, Diagnosis and Management into Health Systems  
Anshu Banerjee, MD, PhD, Director, Department of Maternal, Newborn, Child and Adolescent Health and Ageing, World Health Organization (WHO)

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<th>TIME</th>
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<tr>
<td>18:00 - 18:30</td>
<td>Cultural Program: Chilean National Dance</td>
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<td>18:30 - 20:00</td>
<td>Cocktail Reception</td>
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### THURS | 2 March

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<tr>
<td>08:00 - 17:00</td>
<td>REGISTRATION (Foyer G)</td>
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<tr>
<td>08:30 - 08:45</td>
<td>Welcome and Announcements (Grand Ballroom with Simultaneous Translation)</td>
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<tr>
<td>08:45 - 10:00</td>
<td>PLENARY 1: (Grand Ballroom with Simultaneous Translation)</td>
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P1 PARTNERSHIPS AND PROGRAMS FOR ACCELERATING ACTION FOR BIRTH DEFECTS AND DISABILITIES  
Moderators: Judith Robb-McCord (USA), Cecilia Mellado (Chile)

Partnerships to Strengthen Programs for Public Health Action  
Karen Remley, Centers for Disease Control and Prevention, USA

Large Scale Birth Defects Initiative in South-East Asia Region: Success and Challenges  
Neena Raina, WHO SEARO, India

Strategies and Policy Frameworks for Accelerating Action for Birth Defects in the Americas  
Pablo Durán, WHO PAHO, Uruguay

Births Defects in Chile: Facts and Challenges  
Fernando González, Ministry of Health, Chile
P2 IMPROVING EQUITABLE ACCESS: INTEGRATING INTO THE HEALTH SYSTEM SERVICES FOR SCREENING, DIAGNOSIS AND MANAGEMENT OF BIRTH DEFECTS AMONG NEWBORNS AND CHILDREN IN LMIC SETTINGS

Moderator: Ayesha De Costa (Switzerland), José Poblete (Chile)

Introductory Overview on Improving Equitable Access
Ayesha De Costa, World Health Organization, Switzerland

A Framework for a Sustainable, Equity-centred Service for Congenital Disorders: India as a Case Study
Anita Kar, Birth Defects and Childhood Disability Research Centre, India

Improving Equity and Access to Newborn Screening in Sub Saharan Africa and Community Genetic Services in South Africa
Helen Malherbe, Research and Epidemiology at Rare Diseases South Africa (RDSA), South Africa

Improving Coverage and Quality of Care for People with Birth Defects in Chile: Management of Prevention, Screening, Diagnosis, Treatment, Rehabilitation and Palliative Care
Maria Inés Romero, Ministry of Health, Chile

11:00 - 11:30 POSTER SESSION 1 (Posters 1 – 42)
Networking and Coffee Break (Foyer ABC- G - DEF)

11:30 - 13:00 SIMULTANEOUS SYMPOSIA 1: SYMPOSIUM 1 (ABC Room)

S1 Global Burden of Birth Defects for 2023: Updating the Scope, Data Sources and Model Parameters
Moderator: Kathleen Strong (Switzerland)

Are We Talking About the Same Set of Conditions? Setting a Standard Terminology for the Global Burden of Birth Defects
Helen Malherbe, Rare Diseases South Africa, South Africa

Identifying the Scope of the Global Burden of Birth Defects: Which Conditions are Important in Low- and Middle-income Countries
Hannah Blencowe, London School of Health and Tropical Medicine, UK

Challenges with Data Sources for Prevalence of and Mortality from Specific Birth Defects in Low- and Middle-income Countries
Hannah Blencowe, London School of Health and Tropical Medicine, UK
Jamie Perrin, Johns Hopkins School of Global Health, USA

Model Global Database: How We are Updating the Model and Its Assumptions
Hannah Blencowe, London School of Health and Tropical Medicine, UK
Jamie Perrin, Johns Hopkins School of Global Health, USA
Helen Malherbe, Rare Diseases South Africa, South Africa
SYMPOSIUM 2: (G Room with Simultaneous translation)

**S2 Medical Genetics and Genomics Literacy Essential for Prevention of Birth Defects and Disabilities: Activities from the Latin America Network of Human Genetics-RELAGH**
Moderator: Mariela Larrandaburu (Uruguay)

- **Medical Genetics in Latin America: Breaking Down Barriers with a Focus on Prevention**
  Mariela Larrandaburu, Uruguay Ministry of Public Health; Catholic University of Uruguay

- **Regional and Global Opportunities for Training Tools in Genetics and Medical Genomics**
  Elias Garcia, Western Biomedical Research Center, IMSS, Mexico

- **Importance of Genomics as a Diagnostic Tool in Health Systems**
  Alejandra Mampel, University Hospital of National University of Cuyo, Argentina

- **Strategic Alliances, a Key Element to Improve Health Care in Ibero-America**
  Encarná Guillén, Virgen de la Arrixaca University Clinical Hospital; University of Murcia; Murcian Institute of Biosanitary Research, Spain

SYMPOSIUM 3: (DEF Room)

**S3 Care, Support, and Care Giver Experiences**
Moderators: Joyce Matovu (Uganda), Paula Vargas (Chile)

- **Building Centers of Excellence in Pediatric Cardiac Care and Training**
  Bistra Zheleva, Children’s HeartLink, USA

- **“Mighty Children”: Support Group Program for Caregivers of Children Living with Disability in Afghanistan – Program Development, Feasibility and Acceptability**
  Natalie Evans, Murdoch Children’s Research Institute, Australia

- **The Steps Clubfoot Care Model - South African Case Study**
  Karen Mara Moss, Steps Charity NPC, South Africa

- **Getting to Know the Reality of Caregivers of People with a Rare Disease in Chile**
  Isabel Matute, Universidad del Desarrollo, Chile

- **Improving Family-Centered Nutritional Care for Children with Feeding Difficulties and Disabilities**
  Malia Uyehara, USAID Advancing Nutrition, USA
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<tr>
<td>13:00 - 14:00</td>
<td><strong>Lunch and Networking (Gallery and Café Med Rooms)</strong></td>
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<td>14:00 - 15:30</td>
<td><strong>PLENARY 3: (Grand Ballroom with Simultaneous Translation)</strong></td>
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<td><strong>P3 ADDRESSING MICRONUTRIENT DEFICIENCIES THROUGH FORTIFICATION AND SUPPLEMENTATION FOR THE PREVENTION OF ADVERSE BIRTH OUTCOMES AND BIRTH DEFECTS</strong></td>
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<tr>
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<td>Moderators: Jose Cordero (USA), Rosa Pardo (Chile)</td>
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<td>Maternal Nutrition and Pregnancy and Birth Outcomes</td>
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<td>Kristen Hurley, Johns Hopkins Bloomberg School of Public Health, USA</td>
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<td>Population-level Impact of Folic Acid Fortification: Successes, Challenges, and Recommendations</td>
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<td>Jennifer Williams, Centers for Disease Control and Prevention, USA</td>
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<td>Chilean Policies on Micronutrients: 23-year Experience of Folic Acid Fortification Program for Prevention of Neural Tube Defects</td>
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<td>Cecilia Mellado, Pontificia Universidad Católica de Chile, Chile</td>
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<td>World Health Assembly (WHA) Resolution on Food Fortification with Micronutrients to Prevent Congenital Malformations</td>
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<td>Kemel Ghotme, Fundacion Santa Fe de Bogota, Colombia</td>
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<td>Micronutrient Supplementation in Pregnancy</td>
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<td>Kristen Hurley, Johns Hopkins Bloomberg School of Public Health, USA</td>
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<td>15:30 - 16:00</td>
<td><strong>POSTER SESSION 1 (Posters 43 – 82)</strong></td>
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<td>Networking and Coffee Break (Foyer ABC- G - DEF)</td>
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S4 Prevention Strategies and Knowledge about Interventions
Moderator: Rajesh Mehta (India), Andrea Maccioni (Chile)

A Global Update on the Status of Prevention of Folic Acid Preventable Spina Bifida and Anencephaly in Year 2000: 30-Year Anniversary of Gaining Knowledge about Folic Acid's Prevention Potential for Neural Tube Defects
Vijaya Kancherla, Emory University Rollins School of Public Health, USA

Bhagashree Radhakrishnan, Birth Defects and Childhood Disability Research Centre, India

Facing the Emerging Challenge: A Bird’s Eye View of Birth Defect Surveillance, Care and Prevention in Sri Lanka
Kapila Jayaratne, Family Health Bureau, Sri Lanka

Arsenic Exposure is Associated with Reduced Effect of Folic Acid in Spina Bifida Prevention: a Hospital-Based Case Control Study in Bangladesh
Maitreyi Mazumdar, Harvard University, USA

Profile of Calls for the First Teratogen Information Service in Latin America Through 32 Years
Maria Teresa Vieira Sanseverino, Universidad Federal Do Rio Grande Do Sul, Brazil

Integrated Surveillance Strategy to Support the Prevention of Neural Tube Defects Through Food Fortification with Folic Acid: the Experience of Costa Rica
Adriana Benavides-Lara, Costa Rican Institute of Research and Education in Nutrition and Health (INCIENSA), Costa Rica

SYMPOSIUM 5 (G Room with Simultaneous translation)

S5 Mobilizing Children for Life: Improving Access to Clubfoot Care for Newborns in Low- and Middle-income Countries (LMICs)
Moderator: Salimah Walani (USA)

MiracleFeet's Impact in Making Clubfoot Treatment Accessible and Affordable for Newborns in LMICs
Daphne Sorensen, MiracleFeet, USA

Integrating Clubfoot Care within Paraguay’s National Health Systems
Liza Valdez, Paraguay National Clubfoot Program, Paraguay

The Story of a Baby Born with Clubfoot in Ecuador
Jessica Córdova, Portoviejo Specialty Hospital, Ecuador
S6 Surveillance of Birth Defects in LMICs
Moderators: Neelam Aggarwal (UK), Boris Groisman (Argentina)

**Neural Tube Defects Surveillance in Botswana: 2014-2022**
Modiegi Diseko, Botswana Harvard Aids Institute Partnership, Botswana

**Clinical Characteristics and Early Survival of Infants with Major Congenital Anomalies in Western Kenya**
Audrey Chepkemoi, Moi Teaching and Referral Hospital, Kenya

**Prevalence of Selected Birth Defects in a Hospital-based Birth Defects Surveillance System in Kampala, Uganda, 2015–2021**
Dhelia Williamson, Centers for Disease Control and Prevention, USA

**Burden and Consequence of Birth Defects in Nepal: Evidence from Prospective Cohort Study**
Prajwal Paudel, Paropakar Maternity and Women’s Hospital - Ministry of Health, Nepal

**Birth Defects Surveillance in Resource-Limited Settings: Success Story of Sri Lanka**
Shashika Goonetilleke, Family Health Bureau, Sri Lanka

**India Newborn and Birth Defects Registry- Experiences and Challenges**
Shobhna Gupta, V.M.M.C. and Safdarjung Hospital, India

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**FRI | 3 March**  
**World Birth Defects Day**

**TIME**  
**TOPIC**

08:00 - 17:00  
REGISTRATION (Foyer G)

08:15 - 08:30  
WORLD BIRTH DEFECTS DAY RECOGNITION (Grand Ballroom with Simultaneous Translation)
PLENARY 4: (Grand Ballroom with Simultaneous Translation)

P4 NEWBORN SCREENING FOR METABOLIC AND STRUCTURAL HEALTH CONDITIONS
Moderators: Suzanne Serruya (Uruguay), Gloria Durán (Chile)

Status of Newborn Screening in Latin America: An overview of the Current Situation
Gustavo Borrajo, Biochemical Foundation of La Plata, Argentina

Challenges in the Design and Implementation of Neonatal Screening Program –Paraguay
Marta Ascurra, Ministry of Public Health and Social Welfare, Paraguay

Newborn Screening in the Philippines: Screening, Treatment and Continuing Care beyond Diagnosis
Carmencita Padilla, University of the Philippines Manila, Philippines

Screening Solutions and Global Initiatives Supporting Governments to Prioritize and Improve Child Health in LMICs
Marika Kase, PerkinElmer, USA

Evidence-Based Clinical Guideline on Newborn Screening for Metabolic and Structural Health Conditions: Challenges on the Design, Development and Implementation
Pablo Durán, WHO PAHO, Uruguay

PLENARY 5: (Grand Ballroom with Simultaneous Translation)

P5 ELIMINATING VIOLENCE, STIGMA AND DISCRIMINATION AGAINST PERSONS WITH BIRTH DEFECTS AND DISABILITIES
Moderators: Judith Robb-McCord (USA), Ignacio Zarante (Colombia)

A Hidden Epidemic: Violence Against Children with Disabilities
Ilan Cerna-Turoff, Columbia University, USA

Experiences and Lessons on Violence, Stigma and Discrimination Against Children with Disabilities in Uganda
Clare Bangirana, AfriChild Centre, Makerere University, Uganda

Protecting Children with Birth Defects and Disabilities from Violence and Abuse: Promoting and Honoring Their Human Rights
Esther Masika, Tunu-Africa, Kenya

POSTER SESSION 2 (Posters 43 - 82)
Networking and Coffee Break (Foyer ABC-G-DEF)
S7 Quality and Capacity Building for Birth Defects Surveillance: Data for Action  
Moderators: Paul Romitti (USA), Jorge López-Camelo (Argentina)

The Public Health Burden, Prevention and Care of Infants and Children with Congenital Anomalies in Sub-Saharan Africa: Scoping Review  
Emma Kalk, Centre for Infectious Disease Epidemiology & Research - University of Cape Town, South Africa

Is it Time to Include More Birth Defects in SEAR-NBBD Surveillance System? Analysis of Brief Stakeholder Survey in the South-East Asian Region  
Madhulika Kabra, All India Institute of Medical Sciences, India

Strengthening Capacity of Health Workers to Diagnose Birth Defects in Ugandan Hospitals from 2015-2021  
Joyce Namale-Matovu, Makerere University - Johns Hopkins University Research Collaboration (MUJHU), Uganda

Application of Data Quality Indicators to Hospital-based Birth Defects Surveillance Data, Kampala, Uganda, 2015–2021  
Robert Serunjogi, Makerere University - Johns Hopkins University Research Collaboration, Uganda

Application of Data Quality Indicators to ICBDSR Programs Data  
Boris Groisman, Red Nacional De Anomalías Congénitas De Argentina (RENAC), Argentina

Lorenzo Botto, University of Utah - Division of Medical Genetics, USA

SYMPOSIUM 8 (G Room with Simultaneous Translation)

S8 Screening, Genetics, and Rare Diseases  
Moderators: Carmencita Padilla (Philippines), Marcela Lagos (Chile)

Spectrum of Severe Congenital Ichthyosis in Chile: 10 Years' Experience of the National Ichthyosis Registry  
María-Laura Cossio, Department of Dermatology, Faculty of Medicine, Pontificia Universidad Católica de Chile, Chile

Thalassemia Gene Atlas (TiGA) in China: Pioneering Achievement of Long-Read Sequencing for Birth Defects Prevention  
Desheng Liang, Central South University, China

Prevalence and Clustering of Congenital Heart Defects among Boys with Hypospadias  
Wendy Nembhard, Fay W. Boozman College of Public Health, University of Arkansas for Medical Sciences, USA
Missing Birth Defect Numbers: Where and Which Ones?
Neelam Aggarwal, Post Graduate Institute of Medical Education and Research, India

Surveillance for Birth Defects through Comprehensive Newborn Screening, Developing and Managing an Online Registry to Ensure a Better Quality of Life for Children by Creating Patient Care Pathway and Structured Follow-Up: Model for Low Resource Settings and LMICs
Sreehari Madhavankutty Nair, National Health Mission Kerala, India

Genomic Medicine Clinics for Rare Undiagnosed Disorders - Experience from Global Genomic Medicine Collaborative
Guillermo Lay-Son, Genetics Section, School of Medicine, Pontificia Universidad Católica de Chile, Chile

SYMPOSIUM 9 (DEF Room)

S9 What Drives Success in Pediatric Cardiac Care in Low- and Middle-Income Countries: Closing the Know-Do Gap
Moderator: Bistra Zheleva (USA)

Addressing the Need for Surgical Care for CHD, a LMIC Local Government Perspective
Sreehari Nair, Kerala National Health Mission and Kerala Department of Health, India

Building Hospital Quality Pediatric Cardiac Care, Why Multidisciplinary Care Is Important
Babar Hassan, pediatric cardiology, Sindh Institute of Urology and Transplantation, Pakistan

Using Technology and Telemedicine to Build Capacity for Pediatric Cardiac Care in a Low-resource Setting
Sandra Mattos, Real Hospital Português, Brazil

The International Quality Improvement Collaborative for Congenital Heart Disease, Collaborative Learning in Pediatric Cardiac Surgery is Possible in LMICs
Dana Weber, Boston Children’s Hospital, USA

National Efforts to Address the Burden of Congenital Heart Disease, the Experience of Brazil
Claudia Lidroneta Katz, Ministry of Health, Brazil

13:00 - 14:00 Lunch and Networking (Gallery and Café Med Rooms)

14:00 - 15:30 SYMPOSIUM 10 (ABC Room)

S10 Understanding Birth Defects Risk Factors
Moderators: Jennifer Williams (USA), Silvia Castillo (Chile)
Prevalence of Adverse Birth Outcomes and External Birth Defects Among Women Living with HIV in Malawi
George Bello, International Training & Education Center for Health (I-TECH), Malawi

Risk Factors for Congenital Anomalies and Selected Adverse Pregnancy Outcomes in An Indian Maternal Cohort
Anita Kar, Birth Defects and Childhood Disability Research Centre, India

Risk Factors and Profile of Live Births with Birth Defects in Brazil, 2011 To 2020
Julia Gomes, Ministry of Health of Brazil, Brazil

Major Birth Defects among Offspring of Pesticide Applicators Enrolled in the Iowa Agricultural Health Study Cohort
Paul Romitti, University of Iowa, USA

Maternal Periconceptional Myo-Inositol Intake, Prenatal Alcohol Intake and Risk of Congenital Heart Defects in Offspring
Wendy Nembhard, Fay W. Boozman College of Public Health - University of Arkansas for Medical Sciences, USA

SYMPOSIUM 11 (G Room with Simultaneous Translation)

S11 Birth Defects Surveillance in Latin America and the Caribbean: Experiences, Lessons Learned, and Challenges
Moderator: María Paz Bidondo (Argentina)

Strengthening and Scaling Up National Surveillance Systems of Birth Defects in Latin America and the Caribbean
Pablo Durán, PAHO, Uruguay

Latin American Collaborative Study of Congenital Malformations (ECLAMC): Strategies, Sustainability, and Model of Health Research
López Camelo, ECLAMC, Argentina

Implementing Population-based Active Surveillance of Congenital Anomalies: A Pilot Study in the Rio Grande do Sul state (Brazil)
Lavinia Schuler-Faccini, Universidad Federal do Rio Grande do Sul, Brazil

Congenital Defects and Rare Diseases Surveillance and Prevention Program: PREVERDEC-Colombia
Ignacio Zarante, Pontificia Universidad Javeriana, Colombia

Essential Training of Health Care Professionals Before Surveillance Program Implementation
Rosa Pardo, Hospital Clínico Universidad de Chile, Chile

Use of Online Interactive Forums for Improved Birth Defect Detection, Capacitation, and Health Management
María Paz Bidondo, RENAC, ANLIS Malbran-National Health Ministry of Argentina, Argentina
S12 The Importance of Health Systems in Low- and Middle Income Countries for Management of Congenital Anomalies: Focus on Orofacial Clefts
Moderator: Scott Corlew (USA)

Case Study or Overview of a Program on Orofacial Clefts Embedded in a Public Sector Health System in an LMIC
Scott Corlew, Harvard Medical School, USA

Aspects of the Health System: Facilitating Diagnosis, Referral and Pre-surgical Management
Shankar Rai, Nepal Cleft and Burn Center, Kirtipur Hospital, Kathmandu, Nepal

Aspects of the Health System: Human Resources and Infrastructure for Surgical Care
Kiran Nakarmi, Nepal Cleft and Burn Center, Kirtipur Hospital, Kathmandu, Nepal

Aspects of the Health System: Long-term Follow-up and Care – Necessary Capacities in the Health System
Pramila Shakya, Nepal Cleft and Burn Center, Kirtipur Hospital, Kathmandu, Nepal

15:30 - 16:00 POSTER SESSION 2 (Posters 43 - 82)
Networking and Coffee Break (Foyer ABC - G - DEF)

16:00 - 17:30 SIMULTANEOUS SYMPOSIA 5: SYMPOSIUM 13 (ABC Room)
S13 Birth Defects Screening, Surveillance, and Treatment
Moderators: Helen Malherbe (South Africa), Maria Teresa Sanseverino (Brazil)

Correct Diagnosis of Birth Defects by Health Facility Staff in Four Facilities In Malawi
S. Yamikani Malanga, Centers for Disease Control and Prevention, Malawi

Results of a Health Strategy for the Therapeutic Approach of Oral Clefts in the Public Sub-Sector of Argentina
Paloma Brun, Red Nacional De Anomalías Congénitas De Argentina (RENAC), Argentina

Prenatal Detection of Birth Defects: Structural and Operative Conditions in Obstetric Ultrasound Services in Bogotá, Colombia 2021-2022
Gloria Milena Gracia-Charry, Institute of Human Genetics - Pontificia Universidad Javeriana, Colombia

Detection Rates of a National Fetal Anomaly Screening Programme: National Cohort Study
Sarah Stevens, NHS Digital, UK

Clubfoot Treatment Mobile App for Data-Driven Treatment Adherence, Follow-Up, and Patient Family Support
Jeremy Macias, Hope Walks, USA
S14 Congenital Heart Diseases: Prevention, Diagnosis, and Management  
Moderators: Lorenzo Botto (USA), Guillermo Lay-Son (Chile)

- Population Health Approach for Congenital Heart Disease: Experience from Kerala, India  
  Bistra Zheleva, Children’s HeartLink, USA

- Hridyam for Little Hearts, an Effort to Establish a Care Pathway and Continuum of Care for Children Suspected to have Congenital Heart Diseases to ensure Child Survival and Better Neurodevelopmental Outcome in a Resource Limited Setting for LMICs  
  Sreehari Madhavankutty Nair, National Health Mission Kerala, India

- Surgical Mortality in Pediatric Congenital Heart Surgery: 10-year Experience in a Chilean Cardio-Surgery Center  
  Paula Baquerizo Salgado, Pontificia Universidad Católica De Chile, Chile

- Burden of Congenital Heart Defects in the United States Population, 2010-2014  
  Wendy Nembhard, University of Arkansas for Medical Sciences, USA

- Prevalence & Mortality of Congenital Heart Defects by Race & Ethnicity: Scoping Review  
  Wendy Nembhard, University of Arkansas for Medical Sciences, USA

- Racial/Ethnic Disparities in Health Care Utilization and Mortality Among Individuals with Documented Congenital Heart Defects at Healthcare Encounters, Four U.S. Surveillance Sites, 2011-2013  
  Vijaya Kancherla, Emory University Rollins School Of Public Health, USA

S15 Reversing Destiny: Role of Surgical Care in Birth Defects  
Moderators: Tahmina Banu (Bangladesh), Kokila Lakhoo (UK)

  Hossain Zillur Rahman, Power and Participation Research Centre (PPRC), Bangladesh

- Surgeon’s Perspectives on Birth Defects in Latin America and Africa  
  Doruk Ozgediz, University of California San Francisco, USA

  - Maricarmen Olivos Pérez, Hospital de Niños Roberto del Río, Universidad de Chile, Chile
  - Justina O. Seyi-Olajide, Lagos University Teaching Hospital, Nigeria
NGO Contribution in the Field Through a Focus on Operation Smile
Wieslawa De Pawlikowski, National University of San Marcos, Instituto Nacional de Salud del Niño, Peru

Integrating Clubfoot Care into the Health Systems in Low- and Middle-income Countries
Salimah Walani, MiracleFeet, USA

ICBD 2023 CONFERENCE DINNER
Campus Oriente, Pontificia Universidad Católica de Chile, Jaime Guzmán Errázuriz 3300, Providencia, Santiago
Dress Code: Business Casual/Cultural Dress
<table>
<thead>
<tr>
<th>TIME</th>
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<tbody>
<tr>
<td>08:00 - 10:00</td>
<td>REGISTRATION</td>
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<tr>
<td>09:00 - 10:30</td>
<td>SIMULTANEOUS SYMPOSIA 6: SYMPOSIUM 16 (ABC Room)</td>
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S16 Technology Application in Birth Defects Surveillance  
*Moderators: Cara Mai (USA), Lavinia Schuler-Faccini (Brazil)*

- World Health Organization Digital Adaptation Kit for Creation of a Mobile Application for Birth Defect Surveillance  
  Salimah Walani, World Health Organization, Switzerland
  Caroline Osoro, Center for Global Health Research - Kenya Medical Research Institute, Kenya
- Use of Electronic Data Collection and Web-Based Portal to Ensure the Quality, Timeliness and Accuracy of Final External Birth Defects Diagnosis in Malawi  
  Luke Chiwala, International Training & Education Center for Health (I-TECH), Malawi
- Community-based Birth Defect Surveillance: Innovative Experience from Haryana, India  
  Premananda Mohanty, Survival for Women and Children Foundation, India
- Shiny Application for Monitoring Congenital Anomalies in Rio Grande do Sul, South of Brazil  
  Marcia Barbian, Universidade Federal do Rio Grande do Sul (UFRGS), Brazil

**SYMPOSIUM 17 (G Room with Simultaneous Translation)**

S17 Surveillance and Response to Reduce the Burden Due to Congenital Heart Diseases in the Americas  
*Moderator: Pablo Durán (Uruguay)*

- Evidence on Screening and Response to Reduce the Burden of Disease Due to Congenital Heart Diseases in the Americas  
  Goldy Mazia, Ministry of Health, Argentina; Martin Sabignoso, Argentina
- Situation, Challenges and Advances in the Surveillance and Management of Congenital Heart Disease in Colombia  
  Ignacio Zarante, Pontificia Universidad Javeriana, Colombia
- Argentina National Program for Congenital Heart Defects (PNCC): History and Lessons Learned  
  María Eugenia Olivetti, PNCC, Argentina
S18 Program Development for Birth Defects and Rare Diseases Monitoring and Care Intervention
Moderators: Kapila Jayaratne (Sri Lanka), Adriana Benavides (Costa Rica)

Ushma Mehta, Centre for Infectious Disease Epidemiology & Research - University of Cape Town, South Africa

Experience with the Nicaraguan Registry of Congenital Malformations: Where are We Heading?
Gerardo Mejia, Hospital Infantil Manuel de Jesús Rivera, Nicaragua

Implementing a Multidisciplinary Program for Undiagnosed Rare Diseases in Chile
Gabriela Repetto, Facultad de Medicina, Clinica Alemana Universidad Del Desarrollo, Chile

Establishing National Congenital Anomaly and Rare Disease Registration Service. Our Experience from NCARDRS, England
Sarah Stevens, NHS Digital, UK

Strategic Programming to Increase Access & Strengthen National Capacities for Effective Clubfoot Treatment in Low-and Middle-income Countries
Erin Williams, Hope Walks, USA

10:30 - 11:00 Networking and Coffee Break

11:00 - 12:00 PLENARY 6: (Grand Ballroom with Simultaneous Translation)
P6 THE VOICE OF THE COMMUNITY & PARENT ORGANIZATIONS
Parent perceptions, support, and legal protection on children with disability
Moderators: Hannah Blencowe (UK), Carolina Goic (Chile)

I am a Person First
Esther Masika, founder of Tunu Afrika and parent advocate, Kenya

My life and Work with Individuals with Spina Bifida and Their Families
Genoveva Bahamondes, Spina Bifida Corporation (CORPEB)

Panel with Two Representatives of Parent Organizations
Jessica Cubillos, Federación de Enfermedades Poco Frecuentes Chile (FenpofChile)
Alejandro Andrade, Federación Chilena de Enfermedades Raras (FECHER)

12:00 - 13:00 CLOSING CEREMONY (Grand Ballroom with Simultaneous Translation)

13:00 BOX LUNCH & DEPARTURE