



***International Conference on Birth Defects
and Disabilities in the Developing World***



1 - 4 March 2023 Santiago – Chile



**International Conference on Birth Defects
and Disabilities in the Developing World**
2023 Santiago - Chile

**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
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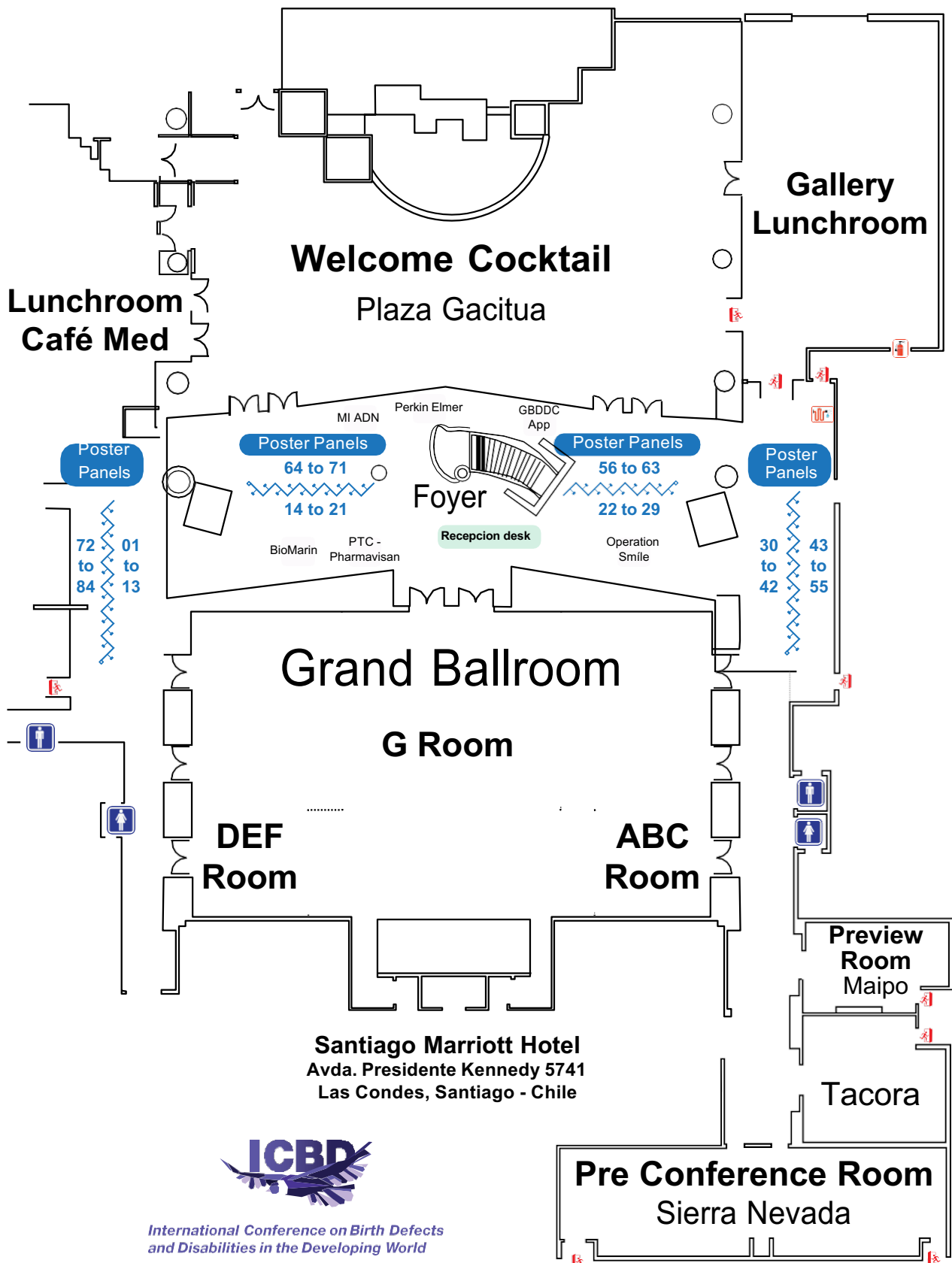
Program at a Glance

	WED 1 March	THURS 2 March	FRI 3 March World Birth Defects Day	SAT 4 March	
8:00		REGISTRATION 8:00-17:00	REGISTRATION 8:00-17:00 8:15 World Birth Defects Day	REGISTRATION 8:00-10:00	8:00
8:30	PRE-CONFERENCE WORKSHOP: Skills Building for Birth Defects Surveillance and Data Utilization (8:30-14:00)	WELCOME PLENARY SESSION 1: (75 min) Partnerships and Programs for Accelerating Action for Birth Defects and Disabilities	PLENARY SESSION 4: (90 min) Newborn Screening for Metabolic and Structural Health Conditions	Simultaneous Symposia 6: (90 min) S16 Technology Application in BD Surveillance S17 Reduce CHD Burden in the Americas S18 Program Development for BD & Rare Diseases Monitoring & Care Intervention	8:30
9:00					9:00
9:30		9:30			
10:00		PLENARY SESSION 2: (60 min) Improving Equitable Access: Integrating into Health System Services for Screening, Diagnosis and Management of BD	PLENARY SESSION 5: (60 min) Eliminating Violence, Stigma and Discrimination Against Persons with Birth Defects and Disabilities		10:00
10:30					Networking and Coffee Break
11:00		Poster Session 1 (Posters 1 – 42), Networking and Coffee Break	Poster Session 2 (Posters 43 – 84), Networking and Coffee Break	PLENARY SESSION 6: (60 min) The Voice of the Community & Parent Organizations	11:00
11:30		Simultaneous Symposia 1: (90 min) S1 Global Burden of BD S2 Medical Genetics & Genomics Literacy for Prevention of BD & Disabilities S3 Care, Support, and Care Giver Experiences	Simultaneous Symposia 3: (90 min) S7 Quality & Capacity Building for BD Surveillance: S8 Screening, Genetics, and Rare Diseases S9 What Drives Success in Pediatric Cardiac Care		11:30
12:00				CLOSING CEREMONY AND DEPARTURE	12:00
12:30					12:30
13:00		Lunch and Networking	Lunch and Networking		13:00
13:30					13:30

	WED 1 March	THURS 2 March	FRI 3 March World Birth Defects Day	SAT 4 March
14:00	REGISTRATION 14:00-16:30	PLENARY SESSION 3: (90 min) Addressing Micronutrient Deficiencies through Fortification and Supplementation for the Prevention of Adverse Birth Outcomes and Birth Defects	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	14:00
14:30				14:30
15:00				15:00
15:30				15:30
16:00				16:00
16:30	OPENING CEREMONY 16:30-18:30 Keynote Address: Anshu Banerjee, MD, PHD	Simultaneous Symposia 2: S4 Prevention Strategies & Knowledge about Intervention S5 Mobilizing Children for Life: Improving Access to Clubfoot Care for Newborns in LMICs S6 Surveillance of BD in LMICs	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	16:30
17:00				17:00
17:30				17:30
18:00				18:00
18:30				18:30
18:30	Cocktail Reception 18:30-20:00	FREE EVENING	ICBD 2023 CONFERENCE DINNER 19:00 Off-site	18:30
19:00				19:00

Conference Venue

Location of Meeting Rooms



Information about Santiago
Learn more about Santiago, transportation,
city tours, museums and other city information.

Program in Detail

WED | 1 March

TIME TOPIC

08:30 - 14:00 *PRE-CONFERENCE: WORKSHOP (Sierra Nevada)*

Skills Building for Birth Defects Surveillance: Focus on Recognition, Description, and Coding

Organized by ICBDSR, CDC, and WHO

10:00 - 11:00 REGISTRATION

10:00 - 11:00 **OPENING CEREMONY** (Grand Ballroom with Simultaneous Translation)

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)

18:00 - 18:30 Cultural Program: Chilean National Dance

18:30 - 20:00 Cocktail Reception

THURS | 2 March

TIME TOPIC

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

08:30 - 08:45 **Welcome and Announcements**
(Grand Ballroom with Simultaneous Translation)

08:45 - 10:00 *PLENARY 1: (Grand Ballroom with Simultaneous Translation)*

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

María 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

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

Elías García, 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

Encarna Guillén, Virgen de la Arrixaca University Clinical Hospital; University of Murcia; Murcian Institute of Biosanitary Research, Spain

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

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

14:00 - 15:30 *PLENARY 3: (Grand Ballroom with Simultaneous Translation)*

P3 ADDRESSING MICRONUTRIENT DEFICIENCIES THROUGH FORTIFICATION AND SUPPLEMENTATION FOR THE PREVENTION OF ADVERSE BIRTH OUTCOMES AND BIRTH DEFECTS

Moderators: Jose Cordero (USA), Rosa Pardo (Chile)

Maternal Nutrition and Pregnancy and Birth Outcomes

Kristen Hurley, Johns Hopkins Bloomberg School of Public Health, USA

Population-level Impact of Folic Acid Fortification: Successes, Challenges, and Recommendations

Jennifer Williams, Centers for Disease Control and Prevention, USA

Chilean Policies on Micronutrients: 23-year Experience of Folic Acid Fortification Program for Prevention of Neural Tube Defects

Cecilia Mellado, Pontificia Universidad Católica de Chile, Chile

World Health Assembly (WHA) Resolution on Food Fortification with Micronutrients to Prevent Congenital Malformations

Kemel Ghotme, Fundacion Santa Fe de Bogota, Colombia

Micronutrient Supplementation in Pregnancy

Kristen Hurley, Johns Hopkins Bloomberg School of Public Health, USA

15:30 - 16:00

POSTER SESSION 1 (Posters 43 – 82)

Networking and Coffee Break (Foyer ABC- G - DEF)

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 Kancharla, Emory University Rollins School of Public Health, USA

Prevention of Congenital Disorders in India Using Existing Maternal Health Interventions: Modelled Estimates from the Modell Global Database of Congenital Disorders

Bhagyashree 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

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)

08:30 - 10:00 *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

10:00 - 11:00 *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-Afrika, Kenya

11:00 - 11:30

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

What Does 'Data for Action' Really Mean? Proposal for Birth Defect Reporting Using the 'Triple Surveillance and Action' Framework

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 Malbrán-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)

'Whole of Society' Approach and Global Initiative for Children's Surgery [GICS] Advocacy Efforts on Early Detection, Management and Capacity-building for Birth Defect Care

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

Doruk Ozgediz, University of California San Francisco, USA

Surgeon's Perspectives on Birth Defects in Latin America and Africa

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

19:00

ICBD 2023 CONFERENCE DINNER

Campus Oriente, Pontificia Universidad Católica de Chile, Jaime Guzmán Errázuriz 3300, Providencia, Santiago

Dress Code: Business Casual/Cultural Dress

TIME	TOPIC
08:00 - 10:00	REGISTRATION
09:00 - 10:30	<i>SIMULTANEOUS SYMPOSIA 6: SYMPOSIUM 16 (ABC Room)</i>

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

Global Birth Defects Description and Coding Application Platform Extension for Expert Panel Review in Surveillance of Congenital Anomalies to Assess Antimalarial Drugs Potential Teratogenicity

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)

The UBOMI BUHLE (Understanding Birth Outcomes from Mothers and Infants, Building Healthcare by Linking Exposures) Pregnancy Exposure Registry in South Africa – a New Platform for Surveillance of Risk Factors for Adverse Birth Outcomes

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 NCARDS, 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**