



9th International Conference on Birth Defects and Disabilities in the Developing World

"Health for All: Accelerate Efforts for Birth Defects Prevention and Care"

23 - 26 February 2020 | Cinnamon Grand Hotel, Colombo, Sri Lanka

DAY 1: Sunday Feb 23, 2020	DAY 2: Monday Feb 24, 2020	DAY 3: Tuesday Feb 25, 2020	DAY 4: Wednesday Feb 26, 2020
08:00 AM – 01:00 PM REGISTRATION	08:00 AM – 5:00 PM REGISTRATION	08:00 AM – 05:00 PM REGISTRATION	08.00 AM – 10:00 AM REGISTRATION
09:00 AM – 03:00 PM PRE-CONFERENCE WORKSHOPS	08:30 AM – 10:00 AM PLENARY SESSION 1	08:30 AM – 10:00 AM PLENARY SESSION 5	08.30 AM – 10.00AM SIMULTANEOUS SYMPOSIA [13-15]
<p>WORKSHOP 1</p> <p>SKILLS BUILDING IN BIRTH DEFECTS SURVEILLANCE</p> <p><i>In Collaboration with WHO, CDC, MoD</i></p> <p>WORKSHOP 2</p> <p>GENOMIC EDUCATION FOR THE MULTI-DISCIPLINARY CARE OF BIRTH DEFECTS</p> <p>In collaboration with the Global Consortium for Genomic Education (GC4GE), Global Genomic Medicine Collaborative, and the Human Genetics Unit, Faculty of Medicine, University of Colombo</p>	<p>PARTNERSHIPS AND PROGRAMS FOR IMPROVING BIRTH DEFECTS SURVEILLANCE</p> <p>Surveillance for Emerging Threats to Pregnant Women and Infants Peggy Honein Centers for Disease Control & Prevention USA</p> <p>Regional Surveillance Programs and Burden of Birth Defects in South East Asia Neena Raina South East Asian Regional Office World Health Organization New Delhi</p> <p>Expanded objectives of birth defects surveillance in developing countries Boris Groisman International Centre for Birth Defects Surveillance and Research Argentina</p> <p>Births Defects Surveillance Efforts in Sri Lanka Kapila Jayaratne Family Health Bureau - Ministry of Health Sri Lanka</p>	<p>UNADDRESSED CHALLENGES OF BIRTH DEFECTS</p> <p>Eliminating Stigma and Discrimination Against Persons with Birth Defects and Disabilities Leivan Bawens International Federation for Spina Bifida and Hydrocephalus Belgium</p> <p>Advocating for National Newborn Screening Programs Carmencita Padilla University of the Philippines, Manila Philippines</p> <p>Unaddressed Challenges of Birth Defects Prevention & Control in Sri Lanka Chithramlee de Silva Family Health Bureau - Ministry of Health Sri Lanka</p> <p>Mobilizing Resources for Care of Children with Congenital Heath Disease in Sri Lanka Duminda Samarasingha Lady Ridgeway Hospital for Children Sri Lanka</p>	<p>SYMPOSIA 13 PRECONCEPTION CARE: ENGAGING CIVIL SOCIETY</p> <p>Organised by Preparing for Life, Netherlands</p> <p>The role of civil society in preconception education Symone Detmar Preparing for life Netherlands</p> <p>The role of Zonta in engaging civil society Dineshani Hettiarachchi Zonta Sri Lanka</p> <p>Youth engagement in preconception care Carmencita Padilla University of Manila Philippines</p> <p>A school based program in the Netherlands Symone Detmar Preparing for Life Netherlands</p> <p>Lessons from voluntarism Rufus Adducul, Volunteer Youth Leaders for Health Philippines</p>

SIMULTANEOUS SYMPOSIUM 14

Sharing Unique Sri Lankan Experiences

Caring for a Newborn with birth defects: Approach to evaluation & management in Sri Lanka
 Surantha Perera
 Castle Street Hospital for Women
 Sri Lanka

Caring for Children in conflict Situations - Sri Lanka's experience
 Sujeewa Amarasena
 University of Ruhuna
 Sri Lanka

The electronic Reproductive Health Information Management System (e-RHMIS) – the country wide digital system for monitoring maternal and child health services in Sri Lanka
 Kaushalya Kasturiarachchi
 Ministry of Health
 Sri Lanka

Genetic Testing for Birth Defects – the Sri Lankan Experience
 Vajira H. W. Dissanayake
 University of Colombo
 Sri Lanka

10.00 AM – 11.00 AM
PLENARY SESSION 2
PREVENTION BEFORE PREGNANCY

A Life course approach to preconception health and pregnancy planning
 Gita Mishra
 University of Brisbane
 Australia

Primary prevention of birth defects
 Cindy Moore
 Centers for Disease Control & Prevention
 USA

10.00 AM – 11.00 AM
PLENARY SESSION 6
FAMILY PLANNING AND ADOLESCENT HEALTH

Organised by United National Fund for Population Activities

SIMULTANEOUS SYMPOSIUM 15

REDUCING RISK FACTORS FOR ADVERSE BIRTH OUTCOMES

OP-47: Changing spectrum and risk factor association in new born babies with birth defects in a tertiary care hospital of North India
 Shobhna Gupta
 India

			<p>OP-48: Pattern and risk factor associated with congenital anomalies in newborn babies born in Dhulikhel Hospital Srijana Dongol Singh Nepal</p> <p>OP-49: Specific Birth Defects in Pregnancies of Women with Diabetes - National Birth Defects Prevention Study, 1997-2011 Cindy Moore USA</p> <p>OP-50: Prevalence, pattern and the association of major structural congenital anomalies with maternal and foetal factors at the Neonatal Care Unit (NICU/SCBU) of a tertiary hospital in Colombo, Sri Lanka Hasani Hewavitharana Sri Lanka</p> <p>OP-51: Pattern of congenital malformations and associated risk factors among neonates admitted at Kenyatta National Hospital, Kenya Everlyn Machogu Kenya</p>
	11:00 AM – 11:30 AM Poster Session, Networking and Coffee Break	11:00 AM – 11:30 AM Poster Session, Networking and Coffee Break	10:00 AM- 10:30 AM Networking and Coffee Break
	11:30 AM – 01:00 PM SIMULTANEOUS SYMPOSIA [1-3]	11:30 AM – 01:00 PM SIMULTANEOUS SYMPOSIA [7-9]	10.00 AM – 12.00 N PLENARY SESSION 9
	<p>SYMPOSIUM 1</p> <p>FOLIC ACID FORTIFICATION FOR IMMEDIATE PREVENTION OF GLOBAL EPIDEMICS OF NEURAL TUBE DEFECTS: GLOBAL EXPERIENCE AND NEXT STEPS IN ASIA</p> <p>Organised by the Center for Spina Bifida Prevention & Food Fortification Initiative, Emory University, USA</p>	<p>SYMPOSIUM 7</p> <p>STRENGTHENING BIRTH DEFECTS SURVEILLANCE FOR SAVING AND IMPROVING LIVES.</p> <p>Organised by the <i>World Health Organization, Geneva</i></p> <p>Strengthening services for managing birth defects Ornella Lincetto World Health Organization Geneva Switzerland</p>	<p>THE VOICE OF THE COMMUNITY & PARENT ORGANIZATIONS</p> <p>Parent perceptions, fear, support and legal protection on children with disability Lasanthi Daskon Sri Lanka</p> <p>Stories of stigma and isolation experienced by persons with birth defects in India Anita Kar India</p>

	<p>Mandatory cereal grain fortification: global status, best practices, and opportunities Scott Montgomery Food Fortification Initiative USA</p> <p>2019 Global Status of Prevention of Folic Acid Preventable Spina Bifida and Anencephaly Vijaya Kancherla Center for Spina Bifida Prevention Emory University USA</p> <p>Preventing neural tube defects in Haryana, India: a project to implement wheat flour fortification in the Public Distribution System and safety net programs Sonia Trikha State Health Systems Resource Centre Haryana State India</p> <p>NTD care and advocacy, its role in fortification Lieven Bauwens International Federation for Spina Bifida and Hydrocephalus Belgium</p> <p>Sri Lanka: Identifying opportunities and the path towards mandatory fortification Renuka Jayatissa Medical Research Institute Ministry of Health Sri Lanka</p>	<p>Current Status of Global Birth Defects Surveillance: Results from 2018-2019 WHO Birth Defects Surveillance Systems Mapping Project Vijaya Kancherla Rollins School of Public Health Emory University USA</p> <p>Birth defects surveillance - Experiences from the recent Zika outbreak Cara Mai Centers for Disease Control and Prevention USA</p> <p>Introduction to the updated WHO birth Defects Atlas - What is new? Nathalie Roos World Health Organization Geneva Switzerland</p> <p>Country perspective from Uganda: Parents voices: children living with a birth defect Sylvia Kyomuhendo and Okello Harrison Infants' Health Foundation Uganda</p> <p>Moderated discussion with questions and answers Rajesh Mehta South East Asia Regional Office World Health Organization India</p>	<p>Giving patients and parents of premature and sick babies in low resource settings a voice Selina Bentoom Ghana</p> <p>Giving women and children a voice for improving their birth outcomes through "Our Dream Initiative" in Egypt Mona Elnaka Egypt</p> <p>Multidisciplinary team involvement in children with disabilities in Sri Lanka Samanmali Sumanasena Sri Lanka</p> <p>12:00 PM- 12: 30 PM</p> <p>Colombo Declaration</p> <p>Closing Remarks by Conference Chairs</p>
	<p>SYMPOSIUM 2</p> <p>LIFE COURSE APPROACHES AND PROGRAMS FOR IMPROVING THE HEALTH OF WOMEN AND GIRLS BEFORE, DURING AND AFTER PREGNANCY</p> <p>OP-01: Workplace Wellness across the Lifespan: A Pilot Program for Health Promotion in a Middle-Income Country Khalid Yunis</p>	<p>SYMPOSIUM 8</p> <p>DIAGNOSTIC STRATEGIES: GENETIC TESTING, NEWBORN SCREENING, PATHOLOGICAL EVALUATIONS</p> <p>OP-21: Molecular signature of preterm premature rupture of fetal membrane Jing Pan China</p>	

	<p>OP-02: Workplace Wellness Modules across the Lifespan: Utilizing e-Learning Access to Knowledge Carmencita Padilla Philippines</p> <p>OP-03: Readiness for implementation of preconception care in Uganda Nathan Isabirye Uganda</p> <p>OP-04: Preconception health care services delivered in selected Medical Officer Areas of Kandy District Sri Lanka Suranga Ubeseckara Sri Lanka</p> <p>OP-05: Impact of antenatal care on stillbirth at a tertiary care referral hospital of India. Nishi Choudhary India</p>	<p>OP-22: The Saudi Human Genome Program (SHGP) and Precision Medicine in Saudi Arabia Aida I Al Aqeel Prince Sultan Military Medical City Saudi Arabia</p> <p>OP-23: The relationship between the essential trace elements in fetal cord blood and congenital heart defects Zhen Liu China</p> <p>OP-24: Genetic service for birth defects at the Dutch Caribbean Islands Eline Verberne Netherlands</p> <p>OP-25: Minimally Invasive Autopsy in the Evaluation of Fetal Malformations Nitika Langeh</p>	
	<p>SYMPOSIUM 3</p> <p>COUNTING BIRTH DEFECTS: INNOVATIONS IN SURVEILLANCE</p> <p>OP-06: Global Birth Defect Inventory of Resources for Surveillance and Research International Committee for Congenital Anomaly Surveillance Tools EUROCAT, ECLAMC, ICBD, CDC, WHO-SEARO, WHO-TDR, MUHJU Helen Dolk UK</p> <p>OP-07: A Reflection of Birth Defect Surveillance in Bangladesh: Challenges and Opportunities Mohammad Shahidullah Bangladesh</p>	<p>SYMPOSIUM 9</p> <p>NETWORKING AND PARTNERSHIPS FOR BIRTH DEFECTS RELATED RESEARCH, PREVENTION AND CARE</p> <p>OP-26: Creating and Strengthening Global Partnerships to End Disability from Clubfoot Alaric Aroojis India</p> <p>OP-27: Combining the strength of government and NGOs, providing comprehensive care for the infants ---An encouraging experience from China Xinliang Zhao China</p> <p>OP-28: Thailand National Plan for Prevention and Care of Birth Defects & Disabilities Pornswan Wasant Thailand</p>	

	<p>OP-08: Integrating Birth Defect Surveillance Midwives into Existing Labor Ward Structures: A Comparison between Government and Private-Not-For-Profit Hospitals in Kampala, Uganda. Joyce Namale Matovu Uganda</p> <p>OP-09: Pattern of congenital anomalies among women opting for Elective termination of pregnancy for fetal anomalies (ETOPFA) Bharti Sharma India</p> <p>OP-10: Comparison of modelled and observed data for isolated oral facial clefts in South Africa Helen Malherbe South Africa</p> <p>OP-11: Overcoming the Defect: A Perinatal Review of Congenital Anomalies in 6984 Consecutive Deliveries in a Tertiary Center in Western Nepal Shreyashi Aryal Nepal</p>	<p>OP-29: The Neonate Fund: Delivering Hope through Facilitating Quality NICU Care Pascale Nakad Lebanon</p> <p>OP-30: Knowledge on advanced maternal age, offspring outcomes and attitudes towards advanced maternal age among pregnant mothers in the Colombo municipal area. Sashiprabha Nawaratne Sri Lanka</p>	
	<p>01:00 PM – 02:00 PM Lunch and Networking</p>	<p>01:00 PM – 02:00 PM Lunch and Networking</p>	
	<p>02:00 PM – 3:00 PM PLENARY SESSION 3</p>	<p>02:00 PM – 3:00 PM PLENARY SESSION 7</p>	
	<p>LINKING BIRTH DEFECTS TO SUSTAINABLE DEVELOPMENT GOALS (2030)</p> <p>An introduction to the 2030 SDGs in the context of child health and birth defects Nathalie Roos World Health Organization Switzerland</p> <p>Surveillance, prevention and care of those with birth defects contribute to countries achieving their SDG child health targets Salimah Walani March of Dimes USA</p>	<p>PREMATURE BIRTH</p> <p>Burden of Preterm Birth in LMICs Razia Pendse Country Office World Health Organization Sri Lanka</p> <p>Scientific Advances in Prevention of Preterm Births Kelle Moley March of Dimes USA</p>	

	<p>Polling to understand the perception of ICBD Conference attendees about birth defects and their relation to SDGs Vijaya Kancherla Center for Spina Bifida Prevention Emory University USA</p>	<p>Advances in care of a baby born too soon or too sick Ornella Lincetto World Health Organization Geneva Switzerland</p>	
	<p>03:00 PM – 4.00 PM PLENARY SESSION 4</p>	<p>03:00 PM – 4.00 PM PLENARY SESSION 8</p>	
	<p>REDUCING EXPOSURE TO HARMFUL SUBSTANCES AND INFECTIONS FOR IMPROVING BIRTH OUTCOMES</p> <p>Impact of Opioids and alcohol on birth outcomes Rahul Gupta March of Dimes USA</p> <p>Medications during pregnancy and birth defects Priyadarshani Galappatthy Department of Pharmacology University of Colombo Sri Lanka</p> <p>Infectious Diseases and Birth Defects Pablo Duran Pan American Health Organization World Health Organization USA</p>	<p>DIGITAL HEALTH STANDARDS AND INTERVENTIONS FOR IMPROVING BIRTH OUTCOMES</p> <p>Birth Defects and Rare Disorders Terminology Matthew Darlison WHO Collaborating Centre for Community Genetics University College London UK</p> <p>A Semantic Information Standard for Global Child Health Elizabeth Siderius Paediatrician GGD IJsselland Netherlands</p> <p>Development of the Global Birth Defects App for Birth Defect Description and Coding International Committee for Congenital Anomaly Surveillance Tools EUROCAT, ECLAMC, ICBD, CDC, WHO-SEARO, WHO-TDR, MUHJU Aminkeng Leke UK</p>	
	<p>04:00 PM – 04:30 PM Poster Session, Networking and Coffee Break</p>	<p>04:00 PM – 04:30 PM Poster Session, Networking and Coffee Break</p>	
	<p>04:30 PM – 06:00 PM SIMULTANEOUS SYMPOSIA [4-6]</p>	<p>04:30 PM – 06:00 PM SIMULTANEOUS SYMPOSIA [10-12]</p>	

SIMULTANEOUS SYMPOSIA 4

EVIDENCE GAPS AND NEW KNOWLEDGE TO SUPPORT NTD PREVENTION ACTIVITIES IN LMICS

Organised by Nutrition International

Introduction: The Folate Task Team
Homero Martinez
USA

Folate status assessment in women of reproductive age: capacity building for Red Blood Cell Microbiological Assay
Renuka Jayatissa
Sri Lanka

Salt as an alternative food vehicle to provide folic acid in select LMIC
Vijaya Kancherla
USA

New Information for Policy Makers to Support the Adoption of Mandatory Large-Scale Food Fortification Programs
Homero Martinez
USA

SIMULTANEOUS SYMPOSIA 10

COUNTING BIRTH DEFECTS: HOSPITAL AND POPULATION BASED SURVEILLANCE

OP-31: Study of Birth Defects in Government Referral Hospital, Maldives 2016-2018
Ahmed Faisal
Maldives

OP-32: A descriptive study on feto-infant structural anomalies in maternal diabetes mellitus: an autopsy study at a tertiary care setting.
S. P. R. V. Lakmini
Sri Lanka

OP-33: Analysis of stillbirth in a tertiary care hospital of Delhi: a contribution to NNBD project
Abha Singh
India

OP-34: Incidence, disease spectrum, and genetic defects in congenital heart disease in China: Prenatal ultrasound screening identified 18,171 affected fetuses from 2,452,249 pregnancies
Xinlin Che
China

OP-35: Birth defects in Congenital Rubella Syndrome-A Hospital Based Surveillance at Tertiary Care Center
Kuldeep Singh
India

OP-36: Neural Tube Defects in China,2007-2017: Data from the National Population-based Birth Defects Surveillance
Changfei Deng
China

SIMULTANEOUS SYMPOSIA 5

REORIENTING HEALTHCARE SYSTEM FOR IMPROVING THE QUALITY OF MATERNAL AND NEWBORN HEALTH SERVICES

OP-12: Training module for primary health care worker for improved recognition and follow up for persons with a congenital disorder
Helen Malherbe
South Africa

OP-13: Implementation of expanded operational guidelines on use of Antenatal Corticosteroids: perspective of program implementers and health care professionals in Northern India
Mona Duggal
India

OP-14: The impact of different intervention packages on facility intervention package on health facility deliveries utilization and other maternal and newborn care practices in Uganda
Peter Waiswa
Uganda

OP-15: Best Wishes Program: Use of mobile phone technology (mHealth) for care coordination directed towards birth defects prevention
Ram Thapa
Nepal

OP-16: The Baby Buddy app: A digital health intervention to bridge neonatal health inequalities in the United Kingdom.
Nilushka Perera
UK

SIMULTANEOUS SYMPOSIA 11

EPIDEMIOLOGIC APPROACHES IN THE STUDY OF PRETERM BIRTH AND BIRTH DEFECTS

OP-37: Global, regional, and national levels and trends in Congenital Birth Defects, 1990-2019
Lauren B. Wilner
USA

OP-38: Bronchopulmonary dysplasia, other comorbidities, and mortality rates associated with extremely premature births in a large medical records database in the United States
Csaba Siffel
USA

OP-39: Epidemiological Profiling from Scientific First Principles - Progress and Prospects of the Modell Global Database of Congenital Disorders
Matthew W Darlison
UK

OP-40: Prevalence and Mortality among Infants with Congenital Diaphragmatic Hernia: A Multi-Registry Analysis
Wendy N. Nembhard
USA

OP-41: Population Medical Genetics approach in clusters of Mucopolysaccharidoses identified in Latin America
Francyne Kubaski
Brazil

OP-42: Spina Bifida Phenotypes and Sex-Specific Prevalence among Offspring of Folic Acid Users
Cynthia Moore
USA

	<p>SIMULTANEOUS SYMPOSIA 6</p> <p>QUALITY OF LIFE STRATEGIES TO REDUCE MORTALITY AND IMPROVE PHYSICAL AND DEVELOPMENTAL OUTCOMES OF CHILDREN WITH BIRTH DEFECTS</p> <p>OP-17: Outcomes of infants with structural birth defects in Galle, Sri Lanka Janithra De Silva Sri Lanka</p> <p>OP-18: Quality of life of primary caregivers having children with congenital heart diseases awaiting cardiac surgery attending at Lady Ridgeway Hospital Pavithra Warnakulasooriya Sri Lanka</p> <p>OP-19: Thalidomide and Zika virus: Lessons for health and welfare systems of low and middle income countries Anita Kar India</p> <p>OP-20: Birth defect in South-East Asian Regional Countries; Challenges and Progress in the Research, Policies and Programmes: A scoping review. Tonima Islam Trisa</p>	<p>SIMULTANEOUS SYMPOSIA 12</p> <p>FOOD FORTIFICATION FOR PREVENTION OF BIRTH DEFECTS</p> <p>OP-43: High Potential for Reducing Folic Acid-Preventable Spina Bifida and Anencephaly, and Related Stillbirth and Child Mortality, in Ethiopia Vijaya Kancherla USA</p> <p>OP-44: Folate and Vitamin B12 status in Women of Reproductive Age in Rural Areas in Haryana, Northern India Reena Das India</p> <p>OP-45: Awareness and factors associated with reported intake of folic acid-fortified flour among women of reproductive age in Ifakara, Morogoro region, Tanzania: A cross-sectional study Ipyana Frank Mwandelile Tanzania</p> <p>OP-46: Potential Level of Global Prevention of Neural Tube Defects with Folic Acid-Fortified Salt Vijaya Kancherla USA</p>	
<p>6:00 PM onwards OPENING CEREMONY</p>		<p>7.30 PM Onwards CONFERENCE DINNER</p>	