

Report on International Conference on Birth Defects and Disabilities 2020

Professor Tahmina Banu

Birth defects affect all nations, but the burden is very high in low- and middle-income countries (LMICs). Although the incidence of birth defects in LMICs is estimated to be 12 per 1000 live births, there are many birth defects that are not reported, so the incidence is likely much higher. Birth defects may cause death, disability, social problems, catastrophic expenditure, abandonment, and even infanticide.

The 9th International Conference on Birth Defects and Disabilities in the Developing World (ICBD 2020) was held in the Cinnamon Grand Hotel, Colombo, Sri Lanka from 23rd to 26th February 2020.

It was organized by the Sri Lanka Medical Association, March of Dimes, US Center for Disease Control and Prevention (CDC), World Health Organization (WHO), and Ministry of Health, Sri Lanka. Other partner organizations included the University of Colombo, Sri Lanka; Sri Lanka College of Paediatricians; College of Community Physicians of Sri Lanka; Health Informatics Society of Sri Lanka; Perinatal Society of Sri Lanka; Sri Lanka Association for Child Development; Sri Lanka Association of Paediatric Surgeons; Sri Lanka Heart Association; Cerebral Palsy Alliance, Australia; Emory University, USA; Commonwealth Medical Association; Genomic Medicine Foundation, UK; Nutrition International, Canada; Preparing for Life, Netherlands and United Nations Population Fund.

Close to 400 leading health care professionals, researchers, and representatives from academic, research, government, international development, and civil society organizations, from 36 countries participated in the conference. Only five surgeons participated, including myself.

Although the theme of the meeting was “Health for All: Accelerate Efforts for Birth Defects Prevention and Care,” nothing about the surgical aspects of birth defects, including fetal surgery, was discussed.

The conference discussed the following topics:

- Using Epidemiologic Surveillance Data for Birth Defects Prevention, Care, and Policy
- Development of Targeted Genomic Education
- Partnerships and programs for improving birth defects surveillance
- Prevention before pregnancy
- Folic acid fortification for immediate prevention of global epidemics of neural tube defects (NTD): Global experience and next steps in Asia
- Life course approaches and programs for improving the health of women and girls before, during, and after pregnancy
- Counting birth defects: Innovations in surveillance
- Linking birth defects to Sustainable Development Goals (2030)
- Reducing exposure to harmful substances and infections for improving birth outcomes
- Evidence gaps and new knowledge to support NTD prevention activities in LMICs
- Reorienting healthcare systems for improving the quality of maternal and newborn health services
- Quality of life strategies to reduce mortality and improve physical and developmental outcomes of children with birth defects
- Unaddressed challenges of birth defects
- Addressing birth defects from the lens of human rights and inclusion
- Strengthening birth defects surveillance for saving and improving lives
- Diagnostic strategies: Genetic testing, newborn screening, and pathological evaluations
- Networking and partnerships for birth defects related research, prevention, and care
- Premature birth
- Digital health standards and interventions for improving birth outcomes

- Counting birth defects: Hospital and population based surveillance
- Epidemiologic approaches in the study of preterm birth and birth defects
- Food fortification for prevention of birth defects
- Sharing unique Sri Lankan experiences
- Preconception care: Engaging civil society
- Reducing risk factors for adverse birth outcomes
- The voice of the community and parent organizations

I was asked to give a 15 minute talk on GICS, titled "GICS and Birth Defects". The topic of NTDs was a big issue in the meeting, I informed them what Prof Diana Farmer is doing with NTDs prenatally. I also chaired a poster session.

I talked to the keynote speaker, Prof Arnold Christianson, and he recognized that surgery must be included in future meetings. He said, "If you cannot do anything about birth defects, go to the surgeon." He might make a good speaker at the next GICS meeting.

Colombo Declaration

Recognizing the need for advocacy for birth defects care and prevention, and in alignment with the Sixty-third World Health Assembly Resolution (2010) on Birth Defects, the participants of the conference had requested the WHO to: 1) Revisit and review the progress in the implementation of the Sixty-third World Health Assembly Resolution WHA63.17 Agenda item 11.7 (2010) and 2) Reinvigorate global efforts to prioritize birth defects prevention and care in the global health agenda.

Also they urged the WHO, international development partners, governments, funders, and the global community to dedicate support and resources to 16 key points and—not surprisingly—only one of the points was about surgery. The point was as follows:

Provide access to treatment and care options, including timely surgical care and rehabilitation for individuals with birth defects and disabilities

Surgery remains neglected on the agenda for birth defects.

Hopefully as a result of the engagement of GICS in this meeting, we shall have some good contacts with the March of Dimes, WHO, CDC, and others. In future meetings, the March of Dimes proposed that GICS would have a slot to hold a plenary session.

I think that children's surgical care providers should be involved in the perinatal societies and neonatal societies of their countries to make a strong presence, so that policy makers listen to our voices and take necessary actions. I also request that Prof Diana Farmer write a simple article on fetal surgery for our neonatal and perinatal colleagues, as well as epidemiologists and others involved with birth defects.