International Clearinghouse for Birth Defects
Surveillance and Research

Monthly Newsletter

November 2025

Issue 2025 - 11

2025 ICBDSR ANNUAL MEETING

The **51st Annual Meeting of the ICBDSR** took place in Magaliesburg, South Africa, from **November 2 to 5, 2025** at the Mount Grace Resort. The meeting consisted of over 50 attendees, 32 abstract presentations, 9 poster presentations and many guest lecturers.

Special thank you to local organizers Emma Kalk & Helen Malherbe and their team for putting together a successful, enjoyable meeting.

Highlights of the Annual Meeting

Preconference Workshop (ICBD). We had a wonderfully active group in the workshop. We enjoyed working together in small groups, learning together, and sharing experiences from diverse backgrounds and skill sets. The goal of the morning was to sharpen our skills of *data quality* assessment and improvement.

In the afternoon, we focused on communication skills, especially on how to *visualize data for increased impact* and understanding – moving from merely 'showing the data' to communicating 'actionable insights'.

Hence, the title of the workshop: "Quality counts, presentation matters: from accurate diagnoses to impactful presentations." We can't wait to see more of you next year in Germany!

Guest Speakers

Welcome from local hosts
Emma Kalk, University of Cape Town & sSCAN
Helen Malherbe, North-West University (NWU) & sSCAN

Keynote
Binu Luke, Lead: Desmond Tutu School of Medicine, NWU

J. David Erickson Lecture - Birth Defects in Africa: A hidden Public Health Crisis
Philippa Musoke, Department of Paediatrics and Child Health, Makerere University, and a Co-Principal Investigator (PI) for the Johns Hopkins University-Uganda, Kampala Uganda

Keynote Lecture - Spina bifida: tip of an iceberg
Graham Fieggan, Helen and Morris Mauerberger Professor and Head;
Director, Neuroscience Institute, University of Cape Town; Head of Clinical Department: Neurosurgery, Groote Schuur Hospital and Red Cross War Memorial Children's Hospital, Cape Town, South Africa

Keynote Lecture - "So what"? Finding meaning and purpose in data
Lorenzo Botto, ICBD Director

ICBDSR Awards presented at the Annual Meeting

Distinguished Service Award 2025
Congratulation to Boris Groisman, RENAC, Argentina!

Lisi-Hurtado Award 2025 – Congratulations to our two winners!
Utibe Ebong – School of Medicine, Ulster University
Samrawit Abebaw Tegene, Hararghe Health Research, Haramaya University

The Social Events

There were many opportunities to network with our colleagues at the meeting including a welcoming reception Sunday evening to kick things off. Monday evening we held a traditional African Braai (BBQ) with an Marimba band on the terrace.

Tuesday many attendees chose to participate in the afternoon tour of the Cradle of Mankind which also included a visit to the Sterkfontein Caves.

The Annual Business Meeting of the ICBDSR – November 5, 2025
With 22 members represented, the Annual Business Meeting covered updates on the Clearinghouse business and the activities of the Executive Committee over the past year.

The ICBDSR welcomed two new Affiliate (individual) members in 2025 – Anwar Baban, Cardiogenetic Center in Bambino Gesù Children Hospital and Research Institute (Rome –Italy) and Helen Malherbe, Rare Diseases South Africa.

We received a proposal from REMACOR - Réunion island Congenital Anomalies Registry (REgistre des MAlformations COngenitales de la Réunion) to join as a new member. The members will be contacted for an electronic vote on the membership.

We welcomed Dieuwke Broekstra, EUROCAT – Netherlands as the newest member of the Audit Committee,

replacing Antonín Šípek Jr (Czech Republic) who has joined the Executive Committee as the Secretary. Mary Ann Thomas (Canada Alberta – ACASS) is now the Chair and Cecilia Mellado (Chile – RENACH) is the Vice-Chair.

Special Thank you to Anke Rißmann & ICBDSR 2026 Annual Meeting

Finishing her term as ICBDSR Executive Committee Chair, Anke Rißmann was thanked by the current committee and members.

As part of the business meeting, Dr. Rißmann proposed to host the ICBDSR 2026 Annual Meeting in Magdeburg, Germany. With full support of the members, the meeting will be **September 13-16th at the University Hospital Magdeburg, Germany.** Further details to come in the new year.

Nominations Committee – Open position

We are also seeking expressions of interest for a member to join the ICBDSR Nominations Committee. Dr. Miriam Gatt, Malta has finished her term with our sincere thanks.

The Nominating Committee, shall be composed of the ICBD director, the Immediate Past Executive Chair and 2 Program Directors. The committee is responsible for proposing members for the Executive Committee. The term is 3 years. If you are interested in serving on the Nominating Committee, please send your name to centre@icbdsr.org for the consideration of the Executive Committee.

Literature corner: this month's selection from the ICBD

Here are papers selected from the recent international literature (last six months) – reference and a curated short summary.

1. Mortality Among Individuals with Congenital Malformations Who Reach Adulthood: Long-Term Follow-Up of the Jerusalem Perinatal Study Cohort
Journal: *International Journal of Epidemiology*, Volume 54, Issue 6, December 2025
Link: **https://pmc.ncbi.nlm.nih.gov/articles/PMC12617745/**

This population-based cohort study from Israel examined long-term mortality risks for 87,621 adults born with congenital anomalies between 1964–1976, with median follow-up of 27.5 years. The study found that individuals with congenital anomalies had a 53% increased risk of premature adult death (adjusted HR 1.53, 95% CI 1.29–1.83), with severe anomalies more than doubling mortality risk (HR 2.21). Cardiovascular anomalies showed the highest risk (HR 4.81), followed by gastrointestinal (HR 2.74) and genitourinary anomalies (HR 1.51). **These findings challenge the perception that congenital anomalies primarily affect childhood survival, demonstrating lifelong health consequences extending well into adulthood**. The findings emphasize urgent need for specialized long-term surveillance and transition care programs for adults with congenital anomalies, particularly those involving the cardiovascular and gastrointestinal systems.

2. Global and Regional Burden of Congenital Birth Defects, 1990–2021: Persistent Healthcare Disparities and Emerging Challenges from Non-Fatal Health Burden
Journal: *BMJ Public Health*, Volume 3, Issue 1, May 2025
Link: **https://pmc.ncbi.nlm.nih.gov/articles/PMC12107580/**

This comprehensive Global Burden of Disease analysis across 204 countries document that while global age-standardized mortality from congenital birth defects declined 47% from 1990 to 2021, the years lived with disability (YLD) rate remained stable, indicating a critical shift from fatal to non-fatal burden. The proportion of YLD in total DALYs increased significantly across all age groups, with over 50% of DALY in populations aged ≥25 years now attributed to non-fatal burden. High-income regions achieved 70% mortality reductions, **while underdeveloped regions in Oceania, Africa and the Caribbean continued to bear disproportionate burden**. Strong negative correlations existed between mortality rates and Healthcare Access and Quality Index, while positive correlations emerged for years lived with disability. This study quantifies **the emerging challenge of lifelong disability** requiring rehabilitation and psychosocial support, demonstrating that progress against fatal outcomes has created an expanding population of adults with complex congenital conditions requiring integrated multidisciplinary care. Healthcare systems must fundamentally shift from acute life-saving interventions to comprehensive chronic disease management models.

3. First Trimester Tetracycline Exposure and Risk of Major Congenital Malformations
Journal: *JAMA Network Open*, Volume 7, Issue 11, November 2024
Link: **https://jamanetwork.com/journals/jamanetworkopen/fullarticle/2826169**

This Swedish population-based cohort study of 1,245,889 births (6,340 exposed to tetracyclines during first trimester) found no increased risk of major congenital malformations overall (RR 1.03, 95% CI 0.90–1.16) or for 10 of 12 malformation subgroups analyzed. **The study provides reassurance about doxycycline and lymecycline safety** with improved precision over prior studies, though initial signals for nervous system (RR 1.92) and eye anomalies (RR 1.76) attenuated substantially in sensitivity analyses with extended follow-up. This is the largest study to date examining tetracycline safety during pregnancy, with robust propensity score matching controlling for confounding. **The research is clinically important because tetracyclines—particularly doxycycline—are among the most commonly prescribed antibiotics in early pregnancy** (used by 3.8% of US pregnancies in first trimester), and existing safety data have been limited and inconsistent. The findings inform evidence-based prescribing decisions and risk communication for common infections requiring antibiotics during pregnancy, balancing treatment necessity against potential fetal risks.

4. Trends in Burden and Mortality of Congenital Birth Defects in G20 Countries (1990–2021) and Predictions for 2022–2040
Journal: *BMC Pregnancy and Childbirth*, Volume 25, April 2025
Link: **https://pmc.ncbi.nlm.nih.gov/articles/PMC12023674/**

This comprehensive analysis of G20 nations (representing two-thirds of global population) **documented 60% decline in congenital birth defect DALYs and 64% decline in deaths from 1990–2021, though significant inter-country disparities persist**. Decomposition analysis revealed epidemiological changes and aging reduced DALYs by 54% and 26% respectively, while population growth increased burden by 21%. Higher sociodemographic index (SDI) and healthcare access and quality (HAQ) indices strongly correlated with lower burden (ρ = -0.78 and -0.83, $p<0.01$), and eleven environmental/nutritional risk factors—particularly occupational noise, unsafe sanitation, and vitamin A deficiency—positively correlated with burden. Bayesian age-period-cohort modeling predicts continued decline through 2040, though countries like India, Mexico, and Brazil will maintain disproportionately high burden. This study identifies modifiable risk factors and quantifies the relative contributions of demographic versus epidemiological changes, demonstrating that **despite medical advances, socioeconomic and healthcare infrastructure disparities drive persistent inequities among the world's largest economies**. The findings emphasize that international cooperation, targeted investments in healthcare resources, and environmental risk mitigation are critical to achieving equitable reductions in congenital birth defect burden globally.

Meetings and Events: A list of future Meetings & Events is available at http://www.icbdsr.org/meetings/.

Human Teratogens – A Live Virtual Course, February 23-25, 2026

The Human Teratogens Course is a unique continuing education opportunity that provides balanced and comprehensive information on the current knowledge and controversies in the field of teratology (birth defect research) and counseling for pregnancy and lactation exposures. National and international experts review basic principles of teratology, embryology, and epidemiology, provide up-to-date information on both common and rare exposures, and present on teratology risk assessment and counseling strategies. The target audience for this course includes obstetricians, maternal fetal medicine specialists, midwifes, genetic counselors, teratogen information specialists, pharmacists, and allied health professionals. This course will take place in a live virtual setting. For more information, please see attachment or visit https://memberaccounts.birthdefectsresearch.org/event/HTCourse2026