52nd International Clearinghouse for Birth Defects Surveillance and Research (ICBDSR)

Annual Meeting & Joint Scientific Meeting with 22nd "Einsendertreffen" at

Medical Faculty Otto-von-Guericke-University Magdeburg, Germany

September 13-16, 2026 (https://www.ovgu.gmbh/veranstaltungen/icbdsr2260)

"Counting What Matters: Data-Driven Advances in Prenatal Diagnosis and Fetal Therapy"

Pre-Conference	**Sunday, September 13**	
13:00 - 17:30	Pre-Conference Workshop "Data Visualization and Storytelling" and builds on the South Africa 2025 workshop" (*at Lecture Hall-Hörsaal 7) Attendance is free, but space is limited and advance registration is required.*	
16:30 - 18:00	*Registration ICBDSR Annual Meeting (at Lecture Hall/Hörsaal - house 7)*	
18:00 - 20:00	**Welcome reception** *(at Lecture Hall/Hörsaal - house 7), "Barbecue"+ old ICBDSR tradition: "Bring a bottle of your favorite wine -one that represents your home country" to share*	
DAY 1	**Monday, September 14- Scientific Sessions** *(at Lecture Hall/Hörsaal - house 7)*	
8:00 - 8:30	Welcome (Meet local organisers, ICBDSR Chair, etc.)	
Session 1:	**Welcome Messages and official opening** **Moderators: Anke Rissmann, Mary Ann Thomas**	
8:30 - 8:50	*Prof. Dr. Daniela Dieterich* is the Dean of the Medical Faculty at Otto von Guericke University Magdeburg (Welcome message *(10 min talk), Group photo of all participants (10 min))*	
8:50 - 9:05	The minister's welcoming address will be delivered by *Dr. med. Angelika Henze*, Ministry of Labour, Social Affairs, Health and Equality of Saxony-Anhalt, Germany *(15 min talk)*	
9:05 - 9:10	*Prof. Dr. med. Antje Redlich*, Children's Hospital Otto-von-Guericke University Magdeburg, Germany *(5 min talk)*	
9:10 - 9:30	ICBDSR Executive Committee Update & Annual Report *Mary Ann Thomas, ICBDSR Chair & Lorenzo Botto, ICBD Director (20 min)*	
9:30 - 10:00	J. David Erickson Lecture: When Signals Become Stories - How We Detect Teratogens and Communicate Risk in Pregnancy *Joan Morris*, Professor of Medical Statistics, Department of Population Health and Policy, University of London *(20 min talk, 5 min discussion)*	
10:00 - 10:30	Strengthening capacity for newborn screening, diagnosis and management of birth defects: a WHO framework for action *Ayesha Mariette De Costa,* MD, MSc, Phd, Scientist, Newborn health Dept of Sexual, Reproductive, Maternal, newborn, child and adolescent health, World Health Organization, Geneva *(20 min talk, 5 min discussion)*	
10:30 - 11:00	**Poster session (Coffee included)** *Poster presenters are expected to be present during their scheduled session, typically standing by their poster to engage with attendees, answer questions, and discuss their research in an informal, one-on-one, or small-group setting. Please see list of Poster 1-8*[i]	
Session 2*:*	**Workshop on Fetal Medicin** *(3 lectures a 20 min + 5 min Q&A)* **Moderators: Anke Rissmann, Cecilia Mellado**	
11:00 - 11:30	Keynote Lecture: Teratogenicity and birth defects in humans *Katarina Dathe*, Institute for Clinical Teratology and Drug Risk Assessment in Pregnancy, Charité-Universitätsmedizin, Berlin, Germany	
11:30 - 12:15	Recent advances in fetal therapy *Ivonne Bedei & Corinna Keil*, Center for Prenatal Medicine and Fetal Therapy, University Hospital Giessen and Marburg, Germany	
12:15 - 13:15	**Lunch & Networking (Break & Poster session)**	
13:15 - 13:40	Recent advances in RASopathies and prenatal testing *Martin Zenker*, Institute of Human Genetics, Medical Faculty, Otto-von-Guericke-University, Magdeburg, Germany (*lecture 20 min + 5 min Q&A)*	
Session 3:	**Birth defect surveillance: global, regional and national** *(15 min + 5 min Q&A)* **Moderators: Cecilia Mellado, Anke Rissmann**	
13:40 - 14:00	Population impact of prenatal diagnosis on live birth prevalence of trisomy 21, 18 and 13 in the Czech Republic	Antonin Sipek Jr

14:00 - 14:20	Agentic artificial intelligence applied to annual Reporting and dynamic data visualization in the National Network of Congenital Anomalies of Argentina (RENAC)	Boris Groisman
14:20 - 14:40	From North to South: What Active Surveillance Reveals About Congenital Anomalies and Inequities in Brazil	Claudia Fernandes Lorea
14:40 - 15:00	Newborn screening and referral for congenital anomalies by lay health workers in Pakistan: a mixed-methods study to evaluate the effectiveness of a co-created educational intervention	Felicity Vidya Mehendale
15:00 - 16:00	**Poster session (Coffee included)**	
Session 4:	**Etiology & Risk Factors** *(15 min + 5 min Q&A)* **Moderators: Claudia Fernandes Lorea, Antonin Sipek Jr**	
16:00 - 16:20	Prenatal whole exome sequencing and the evolving interface between congenital anomaly and rare disease registration	Corinne Mallinson
16:20 - 16:40	Risk Factors Associated with Gastroschisis in Colombia: Preliminary Findings from a Multicenter Case-Control Study	Karen Sarmiento Acuña
16:40 - 17:00	Parvovirus, maternal outcomes, fetal outcomes, congenital anomalies, B19V	Robert Maddison-Jarvis
19:00	*casual professional discussion and networking during **dinner "Biergartenambiente"** (Sponsored by Medical Faculty, Otto-von-Guericke-University Magdeburg) We invite you to an informal exchange of practical experiences across different healthcare systems, following the scientiffic sessions - in a relaxed beer garden setting*	
DAY 2	**Tuesday, September 15 - Scientific Sessions** *(at Central Lecture Hall - house 22)*	
Session 5:	**Birth defect surveillance: global, regional and national Part II** *(15 min + 5 min Q&A)* **Moderators: Boris Groisman, Vijaya Kancherla**	
9:00 - 09:20	Prevalence of Orofacial Clefts in Newborns With Documentation of Outcomes and Challenges in Accessing Care: A Longitudinal Cohort Study in Karachi, Pakistan	Felicity Vidya Mehendale
9:20 - 09:40	Trends in national congenital condition birth prevalence in England between 2018 and 2022 and the impact of accumulated data on reported estimates	Jennifer Broughan
9:40 - 10:00	Utilizing the national newborn screening program to establish a structural birth defect surveillance in the Philippines	Maria Melanie Liberty Alcausin
10:00 - 10:20	Sirenomelia: A review of European prevalence data and epidemiological analysis of 17 cases registered in Wales	Robert Maddison-Jarvis
10:20 - 10:40	CHORNOBYL-related developmental Anomalies (2000-2019)	Wladimir Wertelecki
10:40 - 11:00	**Break & Poster (Coffee included)**	
Awards	**Rare Diseases & Birth Defects** *(15 min + 5 min Q&A)* **Moderators: Cecilia Mellado, Mary Ann Thomas**	
11:00 - 11:15	**Distinguished Service Award Winner**	
11:15 - 11:30	**Lisi-Hurtado Award Winner**	
Session 6:	**Rare Diseases & Birth Defects** *(15 min + 5 min Q&A)* **Moderators: Karen Sarmiento Acuña, Amal Alhashem**	
11:30 -11:50	Disrupted Lives, Broken Bonds and Strained Budgets: Neural Tube Defects and their Psychosocial Burden and Transformative Impacts on Parents	Helina Heluf
11:50 - 12:10	Congenital conditions as rare diseases; evolving registries fit for the modern world.	Kathryn Johnson
12:10 - 12:30	Congenital anomalies in Pentalogy of Cantrell in 25 cases from the Alberta Congenital Anomalies Surveillance System, 1997-2023	Mary Ann Thomas
12:30 - 12:50	Pregnancy infectious diseases screening in Scotland: pregnancy screening for hepatitis B from 1 April 2021 to 31 March 2024	Rachael Wood
12:50 - 13:50	**Lunch & Networking (Break & Poster)**	
Session 7:	**Benefits and controversies of high dose folic acid - What FA dose should clinicians recommend?** Prompted by Vegrim et al. (2022): Cancer Risk in Children of Mothers With Epilepsy and High-Dose Folic Acid Use During Pregnancy. Hybrid Meeting (via ZOOM) with panel discussion **Moderators**: **Anke Rissmann, Mary Ann Thomas**	
13:50 - 14:10	impulse lecture (20 min) *Julie Werenberg-Dreier*, Professor, MsPH, PhD, National Centre for Register-based Research, Department of Public Health Aarhus University, Denmark	

14:10 - 14:30	Maternal high dose folic acid supplementation in pregnancy and risk of childhood cancer: a Target Trial emulation (15 min + 5 min Q&A)	Rachael Wood
14:30 - 15:00	expert panelists: • from EUROCAT: *Joan Morris*, Professor of Medical Statistics, Department of Population Health and Policy, University of London • from UK Teratology Information Service: *Ken Hodson*, MD MRCP(UK) MRCOG, Consultant in Obstetrics and Maternal Medicine, Royal Victoria Infirmary, Newcastle upon Tyne • from clinical Neurology: *Friedhelm Schmitt*, MD, PhD, Epileptology, University hospital Otto-von-Guericke University Magdeburg, Germany	
17:00	***Optional Tour "Discovering Magdeburg"**: Cathedral and Monastery (Walking Tour - about 1,5 hr) personal pay*	
ca.19:00	*included in tour: **Buffett Dinner "Domkönig"***	
DAY 3 -	**Wednesday, September 16 - Annual Business Meeting and Scientific Sessions** *(at Central Lecture Hall - house 22)*	
9:00 - 11:00	**Business Meeting - members only** (additional members per Zoom)	
11:00 - 11:20	**Break & Poster (Coffee included)**	
Session 8:	**Prenatal screening & long term outcome of Birth defects** *(15 min + 5 min Q&A)* **Moderators: Florence Rouget, Antonin Sipek Jr**	
11:20 - 11:40	Clinical Governance and Prenatal Management of Lethal Fetal Anomalies and Genetic Disease in Saudi Arabia	Amal Alhashem
11:40 - 12:00	Mortality Through 2021 Among Persons Born With Spina Bifida in Metropolitan Atlanta, 1981-2018	Vijaya Kancherla
12:00 - 12:20	Morbidity in children with gastroschisis: a population-based data linkage study	Samantha Fisher
12:20 - 13:20	**Lunch & Networking (Break & Poster)**	
13:20 - 13:30	**Poster and Presentation award** *(Focus on data visualization)*	
13:30 - 14:30	**Collaborative Projects & Round table** **Moderators: Mary Ann Thomas, Lorenzo Botto**	
14:30 - 15:00	**Update from other organizations in the field of Birth Defects** (EUROCAT, NBDPN, sSCAN, RELAMC) give 5min report on news regarding: strengthening data quality, harmonising case definitions (SNOMED CT code?) and reporting practices?	
15:00 - 16:00	**World Birth Defects Day (WBDD)**: Discussion on plans for 2027 **Moderators: Anke Rissmann, Vijaya Kancherla**	
16:00	**Official end; Wrap up and close of meeting** *AM organisers & ICBDSR Chair*	
Post- conference	***Thursday, September 17***	
	POST CONFERENCE Day TOUR - Trip to Quedlinbug (World Heritage Site) in Harz Mountains (personal pay)	
	Start 9.00 am by train, visiting castle and town - end is expected around 5.00 pm	

Important Deadlines

- Registration –website https://www.ovgu.gmbh/veranstaltungen/icbdsr2026
- **Deadline 1st August** POST CONFERENCE Day TOUR
- Deadline to book hotel rooms, posponed to: **13th August 2026**
- Authors/presenter to register by: **13th August 2026**
- Attendees to register for **Pre-Conference Workshop: 13th August 2026**
- Abstract booklet deadline - August 1st → for print version

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	Posters (Alphabetical order by corresponding author's name) The posters will be shown during all breaks on Day 1 in the Conference Foyer *(at Lecture Hall-Hörsaal 7)*

1	Uptake of Non-Invasive Prenatal Testing in Saxony-Anhalt, Germany	Anna Sophie Löhr
2	Pitfalls in Clubfoot Identification within a Newborn Screening Program for Birth Defects: A 12-month Experience from Karachi, Pakistan	Felicity Vidya Mehendale
3	Newborn screening for external congenital anomalies in a facility-based cohort in Pakistan	Felicity Vidya Mehendale
4	Determinants of Neural Tube Defects in Eastern Ethiopia: A Community Based Case-Control Study	Helina Heluf
5	Prenatal Exposure to Neuropsychiatric Medications in Colombia: Prevalence, Use Patterns, and Trends from the ECLAMC Study (2004–2019)	Karen Sarmiento Acuña
6	Is SARS-CoV-2 infection (COVID-19) associated with congenital anomalies? A population study of congenital anomaly surveillance data and maternal SARS-CoV-2 infection in Wales.	Samantha Fisher
7	First-trimester non-immune hydrops fetalis: three cases and implications for prenatal diagnosis, Germany	Valeriia Grabar
8	Impact of Mandatory Fortification with Folic Acid on Prevalence of Congenital Heart Defects, Neural Tube Defects, and Orofacial Clefts: A Systematic Review and Meta-Analysis	Vijaya Kancherla