Monthly Newsletter

June 2026

Issue 2026 – 06

ICBDSR 2026 Annual Meeting – REGISTER TODAY!

52nd Meeting of International Clearinghouse for Birth Defects Surveillance and Research Medical Faculty and University Hospital Magdeburg, Germany - September 13 - 16, 2026

The theme of this year's meeting is:
"Counting What Matters: Data-Driven Advances in Prenatal Diagnosis and Fetal Therapy"
REGISTER for the Annual Meeting!

MARITIM Hotel Magdeburg
Book your room early and save! Rooms are available at the rate (10% off) for ICBDSR Annual Meeting participants to **Sunday 5th July** (3 nights) and a limited number of rooms are available for Saturday 12 September for those attending the pre-conference workshop.
Use code: ABK10
Book your hotel room here: https://www.ovgu.gmbh/en/veranstaltungen/icbdsr2026/registration

Pre conference workshop on Sunday, September 13

The workshop runs from 1:00–5:30 pm, allowing participants to arrive the day of and transition directly to the opening reception. This hands-on workshop focuses on data visualization and storytelling and builds on the South Africa 2025 workshop. Attendance is free, but space is limited and advance registration is required.

Post conference tour on Thursday, September 17 - Trip to Quedlinburg

While in Germany, why not add the post conference tour to your registration for a chance to visit this world heritage site? Be sure to register and book the tour by **August 1st** in order to save your spot.

Lisi-Hurtado Award Call for Nominations 2026

At this year's Annual Meeting in Germany, we will be awarding the Lisi-Hurtado Award. For information on the award and eligibility, please visit the ICBDSR website.

Applications - The application package should be sent electronically to the ICBDSR Headquarters (centre@icbdsr.org), and should describe in detail the candidate's accomplishments, current research interests and projects, and why the

nominator believes the candidate's career will promote knowledge of birth defects. Please read the full requirements and eligibility at the link above.

The winner will receive a plaque and a travel stipend to the Annual Meeting of the Clearinghouse.

Deadline for submitting applications is June 30, 2026.

Distinguished Service Award Call for Nominations 2026

At this year's Annual Meeting in Germany, we will be awarding the Distinguished Award. For information on the award and eligibility, please visit the ICBDSR website.

Applications - The application package should be sent electronically to the ICBDSR Headquarters (centre@icbdsr.org), and should describe in detail the candidate's accomplishments, current research interests and projects, and why the nominator believes the candidate's career will promote knowledge of birth defects. Please read the full requirements and eligibility at the link above.

The winner will receive a plaque and a travel stipend to the Annual Meeting of the Clearinghouse.

Deadline for submitting applications is June 30, 2026.

Nominations Committee – Open position

We are also seeking expressions of interest for two members to join the ICBDSR Nominations Committee. Dr. Miriam Gatt, Malta and Dr. Jorge Lopez Camelo are finishing their terms 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.

Nominations are due by June 30, 2026.

ICBDSR Birth Defect Report: data submission notes

Past deadline: May 31, 2026

We appreciate the programs that have completed the data submission. As program leaders and Clearinghouse members, accurate and timely data sharing is a shared responsibility. We are working with program leaders as we move forward with data cleaning and wrangling

For reference, the ICBDSR 2024 report is available HERE. The current plan is to alternate a comprehensive and abbreviated report. The upcoming 2026 report (data submitted 2025) will be the abbreviated report, and the 2027 report (data submitted 2026) will be a comprehensive report. And so on.

New Book Written by Dr. R. Brian Lowry: *From Pediatrics to Medical Genetics: An Irish Doctor's Journey*

A chronicle of R. Brian Lowry's long and full life, From Pediatrics to Medical Genetics: An Irish Doctor's Journey spans Lowry's experiences in wartime Belfast through his more than six decades devoted to medicine, and his role in the pioneering of medical genetics in Canada.

Lowry's memoir highlights the importance of resilience, cheerfulness, and gratitude-as well as family and sports-and his seminal role in the field of medical genetics in Canada. It is at once a piece of medical history in the fields of pediatrics and genetics, a record of World War II experiences (pre-, during, and post-war), and a memoir for family members and future generations.

Proceeds will be donated by Dr. Lowry to Alberta Children's Hospital Foundation. The book is available for purchase at indigo.ca, Friesenpress, Amazon, Barnes & Noble and many other locations.

ICBD corner: congenital anomalies and rare diseases, part 3 — from agenda to action

Making the case. In earlier newsletters we made the case for why birth defects and rare diseases belong together in public health surveillance, and we asked: what are the gaps and priorities? We have received responses, and we thank those who wrote. A few themes are emerging consistently: *surveillance infrastructure* remains the central bottleneck; *genomic sequencing* is identifying rare disease entities faster than ICD-based coding systems can absorb them; and *life-course data* — from perinatal presentation to adult outcomes — are largely absent from both birth defect and rare disease registries.

These gaps point to practical priorities worth discussion at the Magdeburg meeting: minimum cross-network standards enabling collaborations without requiring full structural integration, and working group on coding harmonization and innovation for rare diseases and congenital anomalies that currently lack adequate ICD representation. Send us your reactions or additional priorities at centre@icbdsr.org. We will bring this discussion to Magdeburg in September.

The multicenter skeletal dysplasia study. This study, announced in the May newsletter, is a concrete step in this direction. Skeletal dysplasias — more than 450 heritable bone disorders — are precisely the kind of conditions that fall between birth defect and rare disease registries, are systematically under-ascertained, and require harmonized international data to generate reliable prevalence estimates and outcome data. Many programs have already expressed interest. The **survey is still open (**click here for form). We encourage programs that have not yet responded to do so.

The call for papers from Birth Defects Research: an opportunity for sharing your thoughts, data, and vision. This special issue seeks to stimulate new thinking and dialogue by highlighting current and emerging approaches, persistent gaps, and future directions in surveillance, research, community engagement, and policy at the intersection of birth defects and rare diseases. *Read more about this opportunity in this issue's Literature Review.*

Literature corner: something a bit different.

This month we highlight two items of potential interest to many of you: a brand new publication from WHO and a call for papers for a special issues on birth defects and rare diseases.

1. **Strengthening capacity for newborn screening, diagnosis and management of birth defects.**
   WHO technical consultation on planning and implementing services integrated into national health systems in low- and middle-income countries

As infectious disease mortality declines, birth defects account for a growing share of under-five deaths in low- and middle-income countries (LMICs). UN estimates show the proportion of under-five deaths attributable to birth defects rose from 1% to 4% in sub-Saharan Africa and from 3% to 11% in South Asia between 2000 and 2023. The burden extends beyond mortality—birth defects impose substantial, often underrecognized morbidity across childhood and into later life. With 90% of affected children and 95% of related deaths occurring in LMICs**, integrating newborn screening (NBS) and birth defect management into national health systems is now an urgent priority and a core component of universal health coverage.**

In response, WHO convened five rounds of technical consultations between September 2024 and April 2025, focused on state-led NBS and birth defect management initiatives in LMICs. The consultations drew on experience from front-runner countries that have implemented large-scale national or subnational programs, and included clinicians, researchers, programe staff, NGOs, and—critically—parents and individuals with lived experience. Their purpose was to **consolidate implementable models** and support other LMICs in planning similar initiatives, in alignment with the 2024 World Health Assembly resolution calling on Member States to advance universal NBS, diagnosis, and long-term care for children with birth defects.

The report is available online from WHO and is attached to this newsletter.

2. Call for Papers: The Intersection of Birth Defects & Rare Diseases: A Public Health & Clinical Imperative

Birth Defects Research Journal Special Issue
Initial Submission deadline: November 30, 2026

Rare diseases and birth defects affect a substantial proportion of the global population and have significant public health, economic, emotional, and social impact on individuals, families, and communities. Although many birth defects are not rare, and rare diseases are not confined to birth or the prenatal period, substantial overlap exists between the two, creating important opportunities for alignment across these fields.

More intentional collaboration could advance population-based surveillance, etiologic research, evaluation of health outcomes and access to services, and the development of responsive policies. This special issue seeks to **stimulate new thinking and dialogue by highlighting current and emerging approaches, persistent gaps, and future directions** in surveillance, research, community engagement, and policy at the intersection of birth defects and rare diseases. For example, a proposed paper might explore innovative strategies for integrating rare disease surveillance with birth defects surveillance systems to strengthen data infrastructure and public health impact.

For more information and list of topics of potential interest, follow this link to the journal: **Call for Papers**

17th International Skeletal Dysplasia Society Meeting

Toronto, Ontario, Canada | August 26–29, 2026
For more information, please visit: https://www.isds.ch/index.php?page=isds-2026-meeting

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

International Clearinghouse for Birth Defects Surveillance and Research (ICBDSR)
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