



International Clearinghouse for Birth Defects
Surveillance and Research



Monthly Newsletter

May 2026

Issue 2026 – 05

ICBDSR 2026 Annual Meeting – [REGISTER TODAY!](#)



The 52nd Annual Meeting of the ICBDSR will be held **September 13-16th at the University Hospital in Magdeburg, Germany.**

Call for Abstracts – Deadline Extended to May 25, 2026

The call for abstracts for the ICBDSR 2026 deadline has been extended to May 25, 2026. Submission will be accepted online. Please visit the [ICBDSR 2026 Annual Meeting Website](#) for the abstract guidelines and the link to submit.

The Abstract Themes for this year's meeting include:

- i. Birth defect surveillance and descriptive epidemiology (including surveillance methodology).
- ii. Risk factors for birth defects.
- iii. Rare diseases.
- iv. Molecular genetics / molecular epidemiology / epigenetics and birth defects.
- v. Prenatal screening, early pregnancy / birth/newborn screening and postnatal outcomes.
- vi. Psychosocial impacts of birth defects, quality of life, education, patient perspectives and related topics.
- vii. Birth defect surveillance and research in low- and middle-income countries.

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

Upcoming deadlines: May 31, 2026

As program leaders and Clearinghouse members, accurate and timely data sharing is a shared responsibility. Timely submission allows for data cleaning, query resolution, and report preparation in advance of the annual meeting.

- For 2026, the list and definitions of anomalies remain unchanged from last year. Harmonization efforts will continue. The 2026 data submission form is available on the Clearinghouse website: [2026 Birth Defect Report Data Submission Form](#). Please review the "ReadMe" section carefully. A short video is also included. If you have questions, contact us early.
- Please note the following:
 - Based on feedback, **cases and denominators are now submitted in separate worksheets** (in the same file).
 - **Use the flag fields** to indicate which conditions you are not reporting and why (e.g., not eligible in your program, or unable to submit because privacy policy, and on). The Data Dictionary lists the values in the flag variable to use.
- Members with expertise in programming or web development are invited to contribute to the 2026 report preparation – please contact us at ICBD.
- 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.
- We look forward to your feedback on structure and deadlines directly by email or at the annual meeting.

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](https://www.indigo.ca), [Friesenpress](https://www.friesenpress.com), [Amazon](https://www.amazon.com), [Barnes & Noble](https://www.barnesandnoble.com) and many other locations.

ICBD corner: skeletal dysplasia study proposal

Based on the success of prior collaborative projects, many programs have encouraged us to explore new studies we can do together. After reviewing gaps in the current literature, we propose a new **international, multicenter epidemiologic study of skeletal dysplasias** (osteochondrodysplasias, OCDs) — a group of more than 450 heritable bone disorders classified into 771 distinct entities associated with 552 genes (2023 ISDS Nosology revision).

As a group, their birth prevalence is approximately 3-7 per 10,000, with under-ascertainment consistently noted. Yet population-level data remain limited to single-country studies or specific conditions such as achondroplasia and osteogenesis imperfecta. No international multicenter study has systematically examined prevalence, perinatal outcomes, associated anomalies, and secular trends across the full spectrum using harmonized surveillance data from multiple programs.

We invite you to complete a short five-question survey to express your interest and help us plan next steps. Please complete the **short survey form** (five questions total) – <https://forms.office.com/r/RX0tcTPGkh>

Program leads of interested programs will be contacted to discuss next steps. If you have difficulty accessing the link, please contact us directly by email.

Literature corner: this month's selection from the ICBD

Four recent papers, spanning for very rare disease epidemiology to risk factors and outcomes. If you have trouble accessing the full paper, send us a note at ICBD.

Sirenomelia: A Review of European Prevalence Data and Epidemiological Analysis of 17 Cases Registered in Wales

Journal: <https://onlinelibrary.wiley.com/doi/10.1002/bdr2.70051>

Year: 2026. Study type: Registry-based epidemiologic analysis

Key finding: EUROCAT data from 24 registries found sirenomelia prevalence around 1 per 100,000 births, with more between-region variation than expected by chance.

Useful surveillance paper for rare anomaly prevalence estimation and interpreting regional clusters.

Sibling Recurrence Risk of Non-Chromosomal Birth Defects

PubMed: <https://pubmed.ncbi.nlm.nih.gov/41720596/>

Year: 2026. Study type: Population-based registry study

Key finding: Florida data from 1,372,831 sibling pairs found younger siblings had about twice the odds of any non-chromosomal birth defect when an older sibling was affected, with especially high concordant recurrence for orofacial defects.

Increased Risk of Disabilities in Children and Adolescents With Congenital Heart Disease of Any Severity

Journal: <https://www.ahajournals.org/doi/10.1161/JAHA.125.047246>

Year: 2026. Study type: Retrospective linked-data cohort

Key finding: Children with CHD had higher disability-service use than matched controls, with adjusted odds ratios rising with CHD severity and procedure history.

Periconceptional Use of Analgesics and Severity of Structural Birth Defects

PubMed: <https://pubmed.ncbi.nlm.nih.gov/41821430/>

Year: 2026. Study type: NBDPS exposure-outcome analysis

Key finding: The study used defect severity groups based on 12-month survival and found no association for single-component acetaminophen, while some opioid-containing combinations and hydrocodone had elevated associations with more severe defects.

13th World Congress of Clinical Safety on June 13-14, 2026 – Kyoto, Japan

Hosted by International Association of Risk Management (IARMM). In-person and virtual registration options are available. For more information, please visit: <http://www.iarmm.org/13WCCS/>

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)

Website: www.icbdsr.org

ICBDSR training platform: www.icbdsrtraining.org

Facebook: www.facebook.com/ICBDSR

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