Monthly Newsletter

April 2025

Issue 2025 -04

ICBDSR 2025 Annual Meeting – REGISTRATION NOW OPEN!

The 51st Annual Meeting of the ICBDSR will be held at the **Mount Grace Resort in South Africa from November 2-5, 2025.**

The theme of this year's meeting is:
"Data that Counts: Transforming Lives Through Birth Defects Surveillance"

Please visit the Mount Grace Resort website for details on the beautiful destination.

Registration is now open! Please visit the ICBDSR 2025 Annual Meeting Website for registration, accommodation, and more details.

Pre-Conference Workshop - *Quality counts, visualization matters: from accurate diagnoses to impactful data visualization*

This interactive workshop emphasizes the crucial role of data quality in identifying and tracking birth defects and the practical advantages of clear and effective data visualization. Participants will learn best practices for efficient and accurate diagnosis and reporting of birth defects, including practical checklists and standardized descriptions.

The second part of the workshop will cover fundamental principles of data visualization. Attendees will explore how thoughtfully designed visualizations can simplify complex medical data, enhance stakeholder understanding, and support informed decision-making. Case studies from birth defect surveillance will illustrate how clear visualizations effectively communicate essential information. By the end of this workshop, participants will have acquired practical strategies to improve data quality and utilize visualization to support public health initiatives.

Registration for the Workshop is required, though there is no fee to attend. There is an option to add the Workshop to your ICBDSR 2025 Annual Meeting registration.

Call for Abstracts

We are pleased to announce that the call for abstracts for the ICBDSR 2025 is now open. Submission will be accepted online. Please visit https://icbdsr2025.co.za/call-for-abstracts/ for the abstract guidelines and the link to submit.

Submission deadline is July 11, 2025.

Please note that the International Society for Prenatal Diagnosis (ISPD) Conference https://www.ispdhome.org/ will be in South Africa from October 30 to Nov 2, 2025.

Calls for Nominations

There are several open nominations this year, including one open position on the ICBDSR Executive Committee, the ICBDSR Distinguished Service Award, and the Lisi-Hurtado Award. Please see below for details for each.

ICBDSR Executive Committee Open Position

The ICBDSR Nominations Committee invites all eligible members to send in nominations for the position of **Secretary/Treasurer on the ICBDSR Executive Committee**. As Dr. Anke Rissmann will be leaving the Board, we would encourage European nominations to ensure diversity on the Committee.

Dr. Mary Ann Thomas (Canada) will assume the role of Committee Chair, and Dr. Cecilia Mellado (Chile) will become the Vice Chair.

Nominations should be sent to centre@icbdsr.org no later than **May 31, 2025**. The nominations committee will review all nominations.

Distinguished Service Award 2025

What is the ICBDSR Distinguished Service Award?

The *ICBDSR Distinguished Service Award* honours an individual who has provided distinguished service to the International Clearinghouse.

Eligibility requirements

The recipient must:

- have been part of a Clearinghouse member program or a related office (e.g., ICBDSR Centre) for at least seven years;
- have served the Clearinghouse in the past in some of the following categories: Officer of the Clearinghouse (Executive Committee), Chair of a Committee, Member of a Committee, Editor of the Annual Report, or equivalent service;
- provide evidence of a productive career in Birth Defect Surveillance, Research, or Prevention; and
- demonstrate leadership in the discipline, as evidenced by leadership in surveillance programs and activities, advisory groups, or training of new specialists in birth defect surveillance and research.

Nomination

Nominations should consist of:

1. A nomination letter from an ICBDSR member identifying how the nominee meets the eligibility criteria.
2. A second letter of reference must be provided from another individual who is familiar with the nominee's career. The letters of nomination and references should be sent electronically to the ICBDSR Headquarters (centre@icbdsr.org).

Selection
The Distinguished Service Awards Committee (constituted by the Executive Committee members, ICBD Director, and up to three other members selected every year by the Executive Committee) will select the recipient of this award using the criteria listed above.

Nature of the award
The winner will receive a plaque at the Annual Meeting of the Clearinghouse.

Nominations should be sent to centre@icbdsr.org no later than **May 31, 2025**. The nominations committee will review all nominations.

Lisi-Hurtado Award Call for Nominations 2025

At this year's Annual Meeting in South Africa, 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.

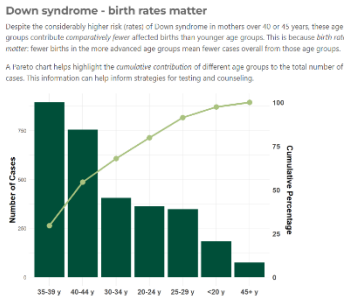
The winner will receive a plaque and a travel stipend to the Annual Meeting of the Clearinghouse.

The deadline for submitting applications is June 30, 2025.

ICBDSR 2025 Annual Report

The 2024 Annual Report is now available. You can view the report HERE. Please note that we have paused data submission for now. New guidelines and directions for the 2025 report will be announced shortly.

ICBD corner



Aside from new updates in the ICBDSR 2024 report (HERE), we are now preparing the list of conditions and associated codes for the 2025 data submission (coming soon). A big thanks to **Dr. Jorieke E.H. van Kammen-Bergman (Northern Netherlands)** and **Dr. Florence Rouget (France-Brittany)** for reviewing and revising the list and codes.
And for those who can make it and are interested in data quality and visualization, we look forward to seeing you at the pre-meeting workshop in South Africa.

News from the ICBDSR and the World

There are many opportunities to advocate for communities and families impacted by birth defects. Consider putting together local activities and joining our many partners: we are stronger together.

- **World Down Syndrome Day (WDSD) Friday, March 21**
    - World Down Syndrome Day (WDSD) is a global awareness day that has been officially observed by the United Nations since 2012.
      The date for WDSD, being the 21st day of the 3rd month, was selected to signify the uniqueness of the triplication (trisomy) of the 21st chromosome, which causes Down syndrome. #WorldDownSyndromeDay. https://www.worlddownsyndromeday.org/

- **World Health Day, Monday, April 7**
  It is celebrated annually and each year draws attention to a specific health topic of concern to people all over the world. The date of 7 April marks the anniversary of the founding of the WHO in 1948. https://www.who.int/campaigns/world-health-day

Literature corner: this month's selection from the ICBD

To find the paper online, use the provided link to PubMed. If interested but unable to get the full text of the papers, please email us, and we will see what we can do to help.

Here are a few interesting papers recently published, focusing on population variations in health outcomes. Assessing population variation with respect to sociodemographic characteristics helps answer questions such as "how might these findings apply to my population?" and "how can I improve population-wide health and outcomes more efficiently and effectively"? These specific papers focus on the US, but the rationale and methods can be (should be?) applied universally. If you have suggestions for other recent papers in other countries and world regions, let us know.

Years of Potential Life Lost for Children and Adults With Congenital Heart Defects: United States, 2007 to 2017. Nembhard WN, Maity S, Bircan E, Politis MD, Bolin EH, Ying J.J Am Heart Assoc. 2025 Mar 18;14(6):e037164. doi: 10.1161/JAHA.124.037164. Epub 2025 Mar 13. PMID: 40079297.
Excerpt: "Children with CHDs experience significant premature deaths. Non-Hispanic Black and male individuals experienced the highest burden of premature deaths associated with CHDs. Further research is needed to elucidate these disparities."

Meta-analysis on sex differences in mortality and neurodevelopment in congenital heart defects. Crain AK, Lim ZN, Sarfatis CJ, Arias M, Holder T, Moreira AG, Corno AF, Findley TO.Sci Rep. 2025 Mar 9;15(1):8152. doi: 10.1038/s41598-025-92894-w.PMID: 40059122.
Excerpt: "Previous studies have reported higher rates of early childhood mortality in female patients and higher rates of neurodevelopmental impairment in male patients with CHD

requiring surgery. Our meta-analysis suggests that these differences may no longer be valid in contemporary surgical cohorts. However, it is unclear if sex-related risk factors have truly been mitigated with current surgical and medical approaches".

Ten Americas: a systematic analysis of life expectancy disparities in the USA.
Dwyer-Lindgren L, Baumann MM, Li Z, Kelly YO, Schmidt C, Searchinger C, La Motte-Kerr W, Bollyky TJ, Mokdad AH, Murray CJ.Lancet. 2024 Dec 7;404(10469):2299-2313. doi: 10.1016/S0140-6736(24)01495-8. Epub 2024 Nov 21. PMID: 39581204

Another assessment of population variations with public health implications. Although it focuses on the US, the study highlights methods and approaches that can be applied to many other countries that have national health statistics data.
Excerpt: " Our analysis confirms the continued existence of different Americas within the USA. One's life expectancy varies dramatically depending on where one lives, the economic conditions in that location, and one's racial and ethnic identity. This gulf was large at the beginning of the century, only grew larger over the first two decades, and was dramatically exacerbated by the COVID-19 pandemic. These results underscore the vital need to reduce the massive inequity in longevity in the USA, as well as the benefits of detailed analyses of the interacting drivers of health disparities to fully understand the nature of the problem. Such analyses make targeted action possible-local planning and national prioritization and resource allocation-to address the root causes of poor health for those most disadvantaged so that all Americans can live long, healthy lives, regardless of where they live and their race, ethnicity, or income.

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

Society for Birth Defects Research & Prevention 65th Annual Meeting June 28-July 2, 2025

Birth defects and reproductive and developmentally-mediated disorders constitute a major public health concern in the world today. Human development can be affected not only by drugs and chemicals but also by diet, genetics, maternal health, and socioeconomic factors. The Society for Birth Defects Research and Prevention strives to understand and protect against potential hazards to developing embryos, fetuses, children, and adults by bringing together scientific knowledge from diverse fields.
Visit the 2025 Annual Meeting - Society for Birth Defects Research and Prevention website for full details.

International Society for Prenatal Diagnosis (ISPD) Conference October 30- Nov 2, 2025

Prenatal professionals and trainees from around the world are invited to join us virtually or in person for the 29th International Conference on Prenatal Diagnosis and Therapy, Thursday-Sunday, 30 October - 2 November 2025, in Cape Town, South Africa!

Preconference courses will held on 30 October 2025. The conference will be held Friday-Sunday, 31 October - 2 November 2025 at the Cape Town International Convention Centre in heart of the "Mother City." Plenary sessions will feature invited speakers, hot topics, and debates on emerging approaches to prenatal diagnosis and therapies. Oral and poster presentations will be selected from peer-reviewed abstracts. Topics include clinical genetics, fetal imaging, fetal therapy and more. Visit https://www.ispdhome.org/ISPD2025/Overview for more information.

International Clearinghouse for Birth Defects Surveillance and Research (ICBDSR)
Website: www.icbdsr.org
ICBDSR training platform: www.icbdsrtraining.org
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