



## Monthly Newsletter

May 2025

Issue 2025 - 05

### 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](mailto: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](mailto: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](mailto: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](mailto: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, with updates. You can view the report [HERE](#). We have prepared updated instructions for data submission for the next report, which we hope will make the process easier for you and more efficient for us. Expect to receive guidelines and submission instructions shortly.

### **ICBD corner**



As noted above, guidelines and submission instructions for the 2025 report will be coming your way in the next weeks. Once more, 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.

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.

Finally, take a look at this month's selection of papers – we have focused on reviews on a few important but somewhat offbeat topics, which tend to cause discussion and perhaps confusion when coding and

classifying some cases. These reviews tend to have nice illustrations that you can use for your teaching and training (e.g, figure on the left on microtia). We hope you will find these papers interesting and helpful, if not now then in the future.

## 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 reviews of topics that may not be well covered in typical training on congenital anomalies.** However, these topics and conditions came into play not infrequently in the differential diagnosis and classification of complex cases. Examples include distinguishing between typical and atypical (e.g., Tessier) clefts, refining the classification and coding of microtia in a registry, diagnosing vascular and lymphatic anomalies (e.g., seen in some fairly common syndromes), understanding commonly associated anomalies in cases of sacral agenesis, and identifying specific subset of disorders of laterality (e.g., related to ciliary disorders).

We hope you will find these papers of interest.

[Tessier Craniofacial Clefts](#). Fernstrum C, Elver A, Hoppe I, Humphries L. Clin Plast Surg. 2025 Apr;52(2):179-191. doi: 10.1016/j.cps.2024.09.002. Epub 2025 Jan 18. PMID: 39986881

[Microtia: A Review](#). Camison L, Lisk RC, Soldanska M. Clin Plast Surg. 2025 Apr;52(2):227-244. doi: 10.1016/j.cps.2024.10.002. Epub 2025 Jan 9. PMID: 39986885

[Congenital and Acquired Chiari Syndrome](#). Friedlander RM. N Engl J Med. 2024 Jun 20;390(23):2191-2198. doi: 10.1056/NEJMra2308055. PMID: 38899696

[Biliary atresia](#). Tam PKH, Wells RG, Tang CSM, Lui VCH, Hukkinen M, Luque CD, De Coppi P, Mack CL, Pakarinen M, Davenport M. Nat Rev Dis Primers. 2024 Jul 11;10(1):47. doi: 10.1038/s41572-024-00533-x. PMID: 38992031 Review.

[Primary Ciliary Dyskinesia](#). Wee WB, Kinghorn B, Davis SD, Ferkol TW, Shapiro AJ. Pediatrics. 2024 Jun 1;153(6):e2023063064. doi: 10.1542/peds.2023-063064. PMID: 38695103

[Renal ciliopathies](#). Devlin LA, Dewhurst RM, Sudhindar PD, Sayer JA. Curr Top Dev Biol. 2025;163:229-305. doi: 10.1016/bs.ctdb.2025.01.009. Epub 2025 Mar 18. PMID: 40254346

[Congenital Vascular and Lymphatic Diseases](#). Jung R, Trivedi CM. Circ Res. 2024 Jun 21;135(1):159-173. doi: 10.1161/CIRCRESAHA.124.323181. Epub 2024 Jun 20. PMID: 38900856

[Sacral Agenesis](#). Sánchez-Romero M, Tlaxcala-Castillo L, Pichardo-Rojas PS, Valencia-Melo MA, Paz-López ÁA, Sánchez-Sagastegui F, Wegman-Ostrosky T; International Sacral Agenesis/Caudal Regression Association. Pediatr Neurol. 2025 Feb;163:27-34. doi: 10.1016/j.pediatrneurol.2024.10.020. Epub 2024 Nov 5. PMID: 39642685

[Anorectal malformations](#). de Blaauw I, Stenström P, Yamataka A, Miyake Y, Reutter H, Midrio P, Wood R, Grano C, Pakarinen M. Nat Rev Dis Primers. 2024 Nov 21;10(1):88. doi: 10.1038/s41572-024-00574-2. PMID: 39572572

**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](http://www.icbdsr.org)

ICBDSR training platform: [www.icbdsrtraining.org](http://www.icbdsrtraining.org)

Facebook: [www.facebook.com/ICBDSR](https://www.facebook.com/ICBDSR)

Instagram: <https://www.instagram.com/icbdsr/>

Twitter: @icbdsr <https://twitter.com/ICBDSR>

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