



## Monthly Newsletter

February 2025

Issue 2025 -02

### ICBDSR 2025 Annual Meeting



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

Please visit the [Mount Grace Resort website](#) for details on the beautiful destination.

More details on the program, registration and abstract submissions will come in early 2025.

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

### 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.

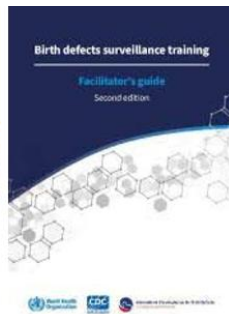
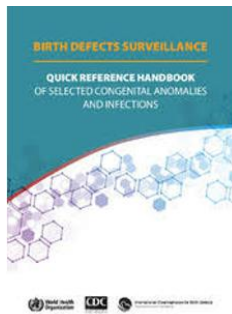
**Deadline for submitting applications is June 30, 2025.**

### ICBDSR 2024 Annual Report

The 2024 Annual Report is now available. You can view the report [HERE](#).

Please note, we have paused data submission for the moment. New guidelines and directions will be announced shortly.

## ICBD corner:



We continue to put the final touches on the birth defect toolkit (left), [now available online](#). In particular, we have developed a slide deck for the case studies in the facilitators manual. Capacity building and training is a major focus at ICBD, so that the benefits of birth defect care and prevention can accrue everywhere, including in low resource areas. Having said this, data quality is a goal in every country and program, and we believe that many managers and frontline staff from well established programs will find something useful in the toolkit.

## News from the ICBDSR and the World: a busy quarter of the year ahead

The first three months of the year provide 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.

- **February 28 is Rare Disease Day** – a special day this year. Rare and Undiagnosed Diseases overlap in our space as clinicians, scientists, and public health professionals. Consider marking this day in your program with an event or celebration. Here is a link where to find ideas and information:
  - <https://www.rarediseaseday.org/>
- **March 3 is World Birth Defects Day** – the Clearinghouse is a founding partner of this event, and this year, as in the past, several members will participate in planning activities. We will share information on ideas and activities as these take form. We hope everyone involved in birth defects will do their best to spread the word about birth defects, their impact, and available solutions – better care and better primary prevention.
  - Sign up as a WBDD partner at [2023 WBDD Partner Form - World Birth Defects Day](#)
  - The [toolkit of resources](#) is still valid to guide your awareness activities for WBDD in 2025.

Twitter: @worldbdday <https://twitter.com/WorldBDDay>

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

Join the WBDD page on Facebook: <https://www.facebook.com/WBDDay/>

## Literature corner: this month's selection from the ICBD

*To find the paper online, use the DOI for a browser search. 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 three interesting papers recently published.

Comorbidities and Healthcare Utilization Among Young Adults With Congenital Heart Defects by Down Syndrome Status—Congenital Heart Survey to Recognize Outcomes, Needs, and

wellbeing, 2016–2019. Vanessa I. Villamil, Karrie F. Downing, Matthew E. Oster, Jennifer G. Andrews, Maureen K. Galindo, Jenil Patel, Scott E. Klewer, Wendy N. Nembhard, Sherry L. Farr. <https://onlinelibrary.wiley.com/doi/full/10.1002/bdr2.2439>

Cognitive, Behavioral and Educational Outcomes in Children Aged 5–11 Years With Spina Bifida in Northern Ireland Yogesh Gopal Parajuli, Marlene Sinclair. <https://onlinelibrary.wiley.com/doi/full/10.1002/bdr2.2434>

[Maternal modifiable factors and risk of congenital heart defects: systematic review and causality assessment.](#)

Gomersall JC, Moore VM, Fernandez RC, Giles LC, Grzeskowiak LE, Davies MJ, Rumbold AR. *BMJ Open*. 2024 Aug 24;14(8):e082961. doi: 10.1136/bmjopen-2023-082961. PMID: 39181550

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

## **Congenital Heart Defect (CHD) Awareness Week – February 7-14, 2025**

February 7-14 is Congenital Heart Defect (CHD) Awareness Week. A congenital heart defect is a structural problem with the heart that is present at birth whether caused by genetic or environmental causes. They can affect the walls of the heart, the valves, or the blood vessels adjacent to the heart, and are the most common type of birth defect affecting about 1% of infants. These defects can range from mild, a small hole in the heart wall that closes on its own, to severe malformations that can be life-threatening. About 25% of infants born with CHD will have critical CHD which will require procedures or surgery in the first year of life.

## **BDRP Annual Meeting – Call for abstracts due February 15, 2025**

The Society for Birth Defects Research and Prevention's 65th Annual Meeting will be in Denver, Colorado, on June 28-July 2, 2025. This year's meeting theme is "Reaching New Heights in Birth Defects Research: Fundamentals to Cutting-Edge Research." The Program Committee, chaired by Prägati Coder, has organized an outstanding program around this theme, and our Education Committee has developed three top-notch continuing education courses, under the leadership of chair Ronee Baracani. Scientific session and course topics.

Visit the [BDRP 65<sup>th</sup> Annual Meeting](#) website for full details.

## **Rare Disease Day – February 28, 2025**

Rare Disease Day is the globally-coordinated movement on rare diseases, working towards equity in social opportunity, healthcare, and access to diagnosis and therapies for people living with a rare disease. <https://www.rarediseaseday.org/>

## **World Birth Defects Day (WBDD) – March 3, 2025**

World Birth Defects Day (WBDD) unites people and organizations working in the field of birth defects, also known as congenital anomalies, congenital disorders or congenital conditions. There are many types of birth defects and this day recognizes our collective voice in raising awareness for all birth defects (**ManyBirthDefects1Voice**). <https://www.worldbirthdefectsday.org>

## **World Down Syndrome Day (WDSD) – March 21, 2025**

World Down Syndrome Day (WDSD) , 21 March, is a global awareness day which 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 – April 7, 2025**

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 WHO in 1948. <https://www.who.int/campaigns/world-health-day>

### ***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)

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