



Monthly Newsletter

March 2026

Issue 2026 – 03

ICBDSR 2026 Annual Meeting – [REGISTRATION NOW OPEN!](#)



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

Call for Abstracts Now Open!

We are pleased to announce that the call for abstracts for the ICBDSR 2026 is now open. Submission will be accepted online. Please visit the [ICBDSR 2026 Annual Meeting Website](#) for the abstract guidelines and the link to submit.

Abstract submissions are due by April 30, 2026.

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.

Affiliate Membership – Proposed Changes - Poll

As has been discussed over several years at the Annual Business Meeting of the ICBDSR, we would like to propose some changes to the Affiliate membership.

We are seeking input and feedback from our members on the proposed categories of Affiliate membership and a dues structure so affiliate members have the opportunity to support the work of the ICBDSR. The results of this poll will be summarized at the next annual meeting and proposed changes will be discussed.

Please read through the proposal and take part in the short survey through the link below to let us know your thoughts.

We have included a comment option for each question for you to provide your feedback. [https://survey.alchemer-ca.com/s3/50524200/ICBDSR-Affiliate-member-dues-poll-2026](https://survey.alchemer.ca.com/s3/50524200/ICBDSR-Affiliate-member-dues-poll-2026)

Responses are due by March 31, 2026.

Nominations Committee – Open position

We are also seeking expressions of interest for a member to join the ICBDSR Nominations Committee. Dr. Miriam Gatt, Malta has finished her term with our sincere thanks.

The Nominating Committee, shall be composed of the ICBDSR 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 schedule for 2026 and 2027

- **31 May 2026**
- **30 April 2027**
- **As program leaders and Clearinghouse members, accurate and timely data sharing is a shared responsibility, and we appreciate your continued commitment to this collaborative effort.** With a shared timeline and clarified submission guidance, we aim to support an efficient workflow and a high-quality, timely report.
- In response to your feedback, we have established a **clear submission timeline for the next two years** to support predictable planning. In 2026, the deadline is 31 May. Beginning in 2027, the annual data submission deadline will be 30 April, and we intend to maintain this date going forward. Timely submission allows us to clean and compile the data, return queries for validation, and prepare the report in advance of the annual meeting.
- **For 2026, the list and definitions of anomalies remain unchanged from last year.** As you are aware, we have worked to harmonize definitions to align more closely with those used by other surveillance networks. We will continue these harmonization efforts in 2026 and welcome constructive input.
- **The 2026 data submission form, with instructions, is available on the Clearinghouse website:**

<http://www.icbdsr.org/resources/2026-birth-defect-report-data-submission-form/>. Based on the previous submission cycle, **we have clarified instructions and slightly tweaked the format of the data forms** in areas that generated unwanted variability in the submissions. We have Please **review the “ReadMe”** section carefully before preparing your submission. Adhering to these guidelines will make data ingestion and quality assessment more automated and reliable, and minimize follow-up queries and resubmissions. If something is unclear or you have questions, questions arise, by all means contact us early so that issues can be resolved promptly.

- **If anyone from the Programs is interested in helping out** in the 2026 report, please reach out to us. Expertise in programming and web development preferred but not necessary.
- For reference, the ICBDSR 2024 report is available [HERE](#). We are currently preparing the 2026 report; a draft will be circulated shortly for your review, and we will discuss it together at the annual meeting in Germany.

ICBD corner: congenital anomalies and rare diseases, part 2

In the last newsletter we started a discussion on **why and how to bring closer the world of birth defects and that of rare diseases**. We made three points. And we have questions for you. First, the points.

First, birth defects and rare diseases intersect in the lives of people. They affect the same babies and children (and adolescents and adults), are evaluated in the same or similar settings (newborn units, pediatric hospitals, etc.) and together lead to significant morbidity and mortality. In fact, some birth defects are rare diseases, and many rare (genetic) diseases include birth defects in their presentation. Rare diseases, much as birth defects, are collectively common (300 million globally) – *treating them as individual clinical problems rather than public health targets is a policy failure*.

Second, babies and children with either set of conditions are seen by the same people (birth attendants, nurses, pediatricians, geneticists, and so on). Their clinical findings are documented in the same or similar data sources and databases. What this means is that identifying and tracking both sets of conditions would require some planning and training but not an entirely new set of processes and data sources. Newborn screening can serve as a proof of concept – *a population-level system that identifies and tracks a specific subset of rare diseases in ways that have proven to be effective and cost-justified*.

Third, there is power in both worlds, a power that can be harnessed to shine the light on both sets of conditions and bring about new energy and better outcomes. Interest in rare diseases is comparatively recent but has grown considerably in recent years, with increasing buy-in from communities, professional institutions, and policymakers. Birth defect surveillance can learn and participate in this evolution to reach shared goals. Conversely, the world of rare disease can benefit from the experience and expertise of birth defect surveillance and public health tracking on issues such as rigorous, population-based assessment of prevalence and outcomes. *Surveillance infrastructure is the bottleneck. Without standardized registries, appropriate coding, and population-based case ascertainment, epidemiological evidence remains too thin to drive policy, fund research or treatments and prevention, or measure intervention impact*.

Now the questions. As professionals – epidemiologists, clinicians, data scientists – **what are the gaps that you see in the worlds of birth defects and rare disease and what do you see as priorities for new data and projects?** In the last issue, under the rubric of ‘literature selection’, we noted that few papers have addressed these issues so far (in this issue, we selected a few more). Send us a note (email to ICBDSR) with your ideas and comments – let’s build a public health agenda together.

Literature corner: this month’s selection from the ICBDSR

Here are selected papers on the intersection of congenital anomalies and rare disease. Interestingly, we have not found many papers that address this issue – if you have additional references or examples, let us know so we can share in future newsletters.

We received and share the following report:

EUROCAT Special Report: Congenital Anomalies are a Major Group of Mainly Rare Diseases. December 2012

Direct link: <https://eu-rd-platform.jrc.ec.europa.eu/sites/default/files/eurocat-pub-docs/Special-Report-Major-Group-of-Mainly-Rare-Diseases.pdf>

In this report from 2012, it was noted that 69 EUROCAT subgroups were rare (< 5 per 10,000) by EU definition, with a total live birth prevalence of 96.23 per 10,000. The authors estimated that this prevalence corresponded to about 4.7

million people in the European Union, and over 50,000 affected live births in the same area per year (27 countries). Using these same data, they estimated that 12-15% of the people estimated at the time to have rare diseases had rare congenital anomalies.

To continue the theme in this month's ICBDR Corner, here is a focused selection of papers on the intersection of public health and rare diseases, published in the last several years, with considerations to help us think about intersections and partnerships with birth defect programs.

Khoury MJ et al. "From public health genomics to precision public health: a 20-year journey." Genetics in Medicine 20:574–582, 2018.

Open access: <https://pubmed.ncbi.nlm.nih.gov/29240076/>

In 1997, CDC's public health genetics focus was limited to newborn screening, birth defects, developmental disabilities, and rare diseases. By 2022, genomic applications had expanded across the lifespan to include expanded carrier testing, noninvasive prenatal testing, genetic testing of sick infants and children with multiple birth defects and neurodevelopmental disorders, and genomic applications for adult cancer and heart disease, with population screening beyond the newborn period now under active exploration. CDC This paper provides a thoughtful 20-year retrospective of the CDC program and explicitly frames rare disease/birth defect genomics as the historical foundation of the broader public health genomics enterprise.

Valdez R et al., The need for a next-generation public health response to rare diseases. Genetics in Medicine volume 19, pages 489–490 (2017).

<https://www.nature.com/articles/gim2016166>

In this report, the authors argue that given 80% of all rare diseases may be caused by genes, genomics is a necessary addition to the public health response to the burden of rare diseases, and that genomic diagnosis can help end the diagnostic odyssey experienced by many rare disease patients. The paper uses burden-of-disease measurement as the entry point — noting that standard measures from simple mortality to complex disability-adjusted life years have been applied to approximately 300 conditions affecting millions worldwide — and calls for applying this same rigor to rare diseases systematically.

El-Sayed AA et al. The role of public health in rare diseases: hemophilia as an example. Front. Public Health, 19 March 2025. Volume 13 - 2025 | <https://doi.org/10.3389/fpubh.2025.1450625>

<https://www.frontiersin.org/journals/public-health/articles/10.3389/fpubh.2025.1450625/full>

In this paper, the authors use hemophilia as a concrete model for what a population-health approach to rare diseases requires in practice. Public health objectives for rare diseases should focus on accurately estimating epidemiological and economic burden through expanding newborn screening, strengthening surveillance systems, assessing costs from a societal perspective, supporting policy formulation, boosting research through international collaborations, empowering patients and caregivers, and ensuring equitable access. As in birth defect surveillance, long-term population registries could improve data collection methods, enhance accuracy of epidemiological estimates, and support informed decision-making for disease management and reductions in preventable complications.

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

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