



Monthly Newsletter

January 2024

Issue 2024 -01

Save The Date: 2024 Annual Meeting September 1 to 4, 2024, Prague (Czech Republic)

The meeting will celebrate 50 years of ICBDSR (1974 – 2024) and 60 years of congenital anomaly registration in Czech Republic (1964 – 2024). Details on hotel reservations and program registration are coming soon.

ICBD corner: ICBDSR Report and Gene-Environment Database

ICBDSR Report -- getting close... but need your help to get to the finish line. We received data, edits, and feedback from most programs and are assembling the report. We are still missing updates from a few programs – please get your information to us as soon as possible (you will have received requests by email, including a recent reminder). Having the report out by World Birth Defects Day would be wonderful!

Gene-environment interactions? This month's data spotlight is on a remarkable database that compiles curated information on how environmental factors affect health and interact with genes (gene-environment interactions). The Comparative Toxicogenomics Database, supported by the NIH, truly is a treasure trove. Explore it at <https://ctdbase.org/>.

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.

- **January** is **National Birth Defects Awareness Month**. Our sister organization, the (US) National Birth Defect Surveillance Network, has prepared a helpful toolkit and is hosting webinars – for details, go to <https://www.nbdpn.org/bdam.php>
- **February 29** 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 are a few links where to find ideas and information:
<https://www.rarediseaseday.org/> - <https://rarediseases.org/rare-disease-day/>
- **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.
 - X (former Twitter) : @worldbdday <https://twitter.com/WorldBDDay>
 - Instagram: worldbdday <https://www.instagram.com/worldbdday/>
 - Join the WBDD page on Facebook: <https://www.facebook.com/WBDDay/>

A selection from the recent literature– spotlight this month on outcome studies

Please send suggestions to centre@icbdsr.org by the 1st Friday of the month.

[Racial and ethnic differences in infant survival for hydrocephaly-Texas, 1999-2017](#). Ahmed M, Shumate C, Bojes H, Patel K, Agopian AJ, Canfield M. Birth Defects Res. 2023 Dec 18. doi: 10.1002/bdr2.2285. Online ahead of print. PMID: 38111285

[Bullying among children with heart conditions, National Survey of Children's Health, 2018-2020.](#) Wright BN, Glidewell MJ, Downing KF, Vagi KJ, Fundora MP, Farr SL. *Cardiol Young*. 2023 Dec 19:1-9. doi: 10.1017/S1047951123004225. Online ahead of print. PMID: 38111963

[Neonatal Outcomes of Critical Congenital Heart Defects: A Multicenter Epidemiological Study of Turkish Neonatal Society : Neonatal Outcomes of CCHD.](#) Dilli D, Akduman H, Zenciroğlu A, Çetinkaya M, et al.. *Pediatr Cardiol*. 2023 Dec 28. doi: 10.1007/s00246-023-03362-z. Online ahead of print. PMID: 38153547

[Publicly funded healthcare costs associated with orofacial clefts for children born in Alberta, Canada between 2002 and 2018.](#) Bedard T, Lowry RB, Crawford S, Wang TG, Bakal J, Metcalfe A, Harrop AR, Grevers X, Thomas MA. *Birth Defects Res*. 2024 Jan 5. doi: 10.1002/bdr2.2295. Online ahead of print. PMID: 38179866

[Oral health-related quality of life in patients aged 8 to 19 years with cleft lip and palate: a systematic review and meta-analysis.](#) de Oliveira Júnior AG, Montagna E, Zaia V, Barbosa CP, Bianco B. *BMC Oral Health*. 2023 Sep 16;23(1):670. doi: 10.1186/s12903-023-03382-4. PMID: 37716942

[Parent-Reported Health-Related Quality of Life Outcomes and Impact on Family of Congenital Diaphragmatic Hernia Survivors After Repair: A Cross-Sectional Comparison to Healthy Controls.](#) Rajasegaran S, Nooraziz AN, Abdullah A, Sanmugam A, Singaravel S, Gan CS, Nah SA. *J Pediatr Surg*. 2023 Dec 10:S0022-3468(23)00739-X. doi: 10.1016/j.jpedsurg.2023.12.007. Online ahead of print. PMID: 38160184

[Adult urological outcomes for patients with anorectal malformation.](#) Reppucci ML, Harris KT, Wilcox DT, Peycelon M, Bischoff AJ. *Pediatr Urol*. 2023 Dec 22:S1477-5131(23)00571-5. doi: 10.1016/j.jpuro.2023.12.015. Online ahead of print. PMID: 38184446

A few more notable papers: congenital anomalies and cancer, antifungal medication

[Role of non-chromosomal birth defects on the risk of developing childhood Hodgkin lymphoma: A Children's Oncology Group study.](#) Peckham-Gregory EC, Boff LM, Schraw JM, Spector LG, Linabery AM, Erhardt EB, Ribeiro KB, Allen CE, Scheurer ME, Lupo PJ. *Pediatr Blood Cancer*. 2023 Dec 25:e30822. doi: 10.1002/pbc.30822. Online ahead of print. PMID: 38146016

[Germline mutations in cancer predisposition genes among pediatric patients with cancer and congenital anomalies.](#) Dangoni GD, Teixeira ACB, da Costa SS, Scliar MO, Carvalho LML, Silva LN, Novak EM, Vince CSC, Maschietto MC, Sugayama SMM, Odone-Filho V, Krepischi ACV. *Pediatr Res*. 2024 Jan 5. doi: 10.1038/s41390-023-03000-7. Online ahead of print.

[Antifungal medication use during pregnancy and the risk of selected major birth defects in the National Birth Defects Prevention Study, 1997-2011.](#) Papadopoulos EA, Howley MM, Fisher SC, Van Zutphen AR, Werler MM, Romitti PA, Browne ML; National Birth Defects Prevention Study. *Pharmacoepidemiol Drug Saf*. 2023 Dec 19. doi: 10.1002/pds.5741. Online ahead of print. PMID: 38112229

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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