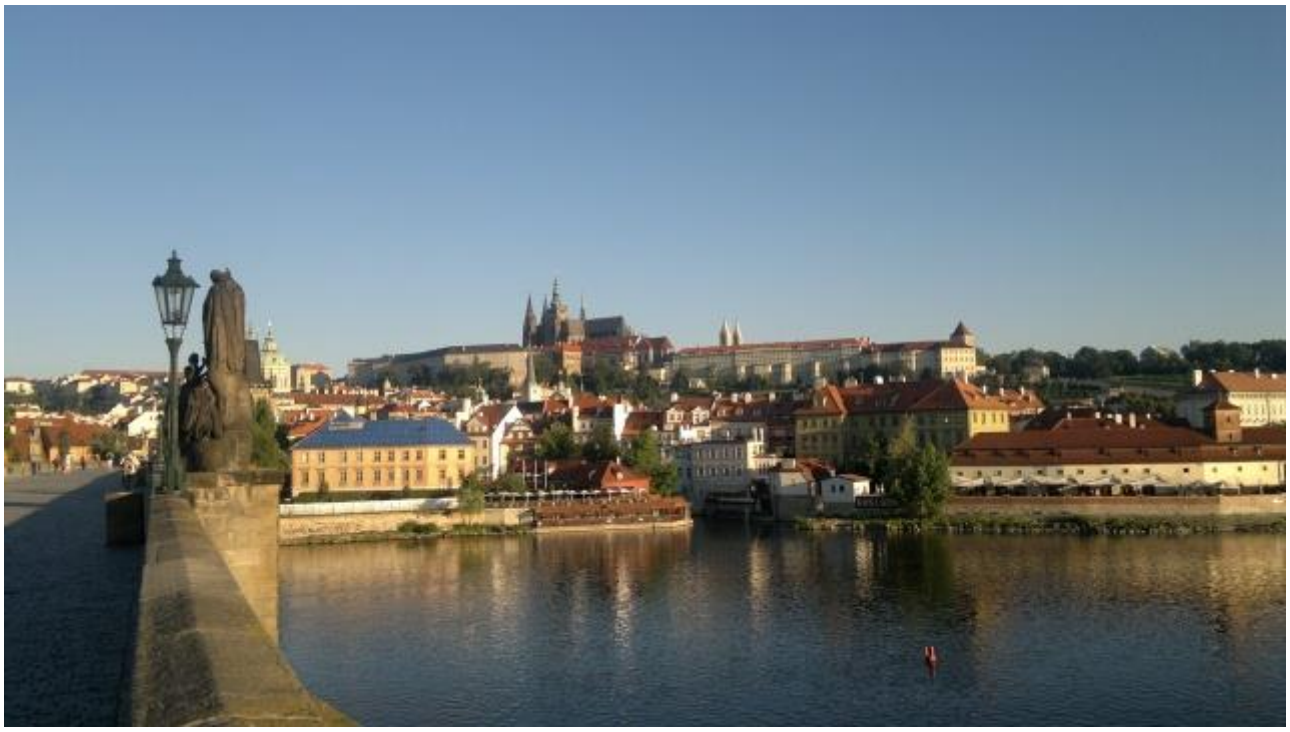
International Clearinghouse for Birth Defects
Surveillance and Research

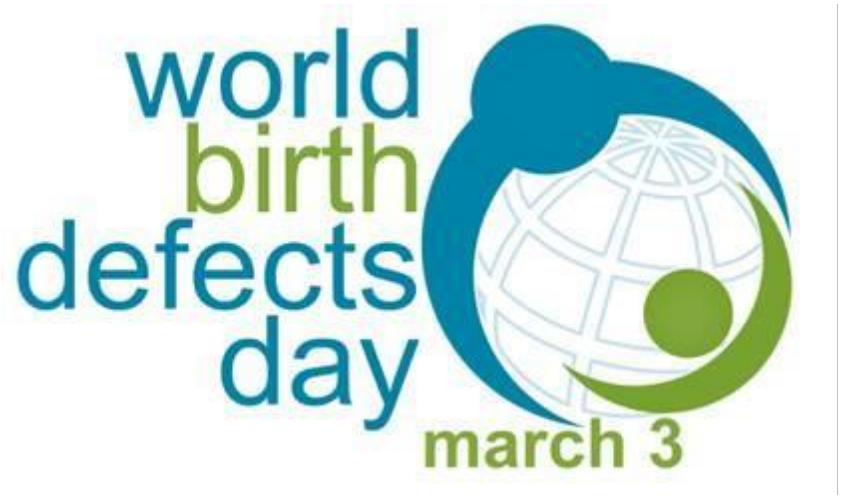
45th Annual Meeting of the International Clearinghouse for Birth Defects Surveillance and Research (ICBDSR)



September 30 – October 4, 2018
Prague, Czech Republic
Hotel Olšanka–Hall Praha

Organized by the ICBDSR and
The National Registry of Congenital Anomalies of the Czech Republic

The International Clearinghouse for Birth Defects Surveillance and Research (ICBDSR) is a Promoting Organization of



www.worldbirthdefectsday.org

Annual Meeting and Workshop-Planning Committee (in alphabetic order):

Lorenzo Botto
Marcia Feldkamp
Boris Groisman
Pierpaolo Mastroiacovo
Paul Romitti
Antonin Šípek Jr
Simonetta Zezza

Acknowledgments:

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MARCH OF DIMES

The ICBDSR is grateful to the Bogotá Congenital Malformations Surveillance Program (BCMSP) which skillfully printed this meeting program. Secretaría de Salud de Bogotá - Pontificia Universidad Javeriana.

REPROMEDA
BIOLOGY PARK
We are your guide
on the path to a complete family

GENNET

The ICBDSR Executive Committee and ICBDSR Centre Staff *want to thank* ***all ICBDSR members****, who work in birth defects surveillance and research, individually as well as in the ICBDSR, to achieve our common goal of* ***primary prevention of birth defects, to help ensure that infants worldwide are born healthy.***

Program

Sunday, September 30, 2018	
09:00 – 13:00	Executive Committee Meeting
14:00 – 18:00	Meeting of the World Birth Defects Day Partner Organizations - *Lounge Plzeň*
16:00 – 18:00	*Registration for the ICBDSR Annual Meeting*
19:30 Welcome cocktail at Hotel Olšanka – offered by the ICBDSR	

Monday, October 1, 2018	
Scientific Session – Moderator: Marcia Feldkamp	
08:30 – 09:00	**Welcome** *Antonin Šípek Jr, Institute of Biology and Medcial Genetics, Charles University, 1st Faculty of Medicine and General University Hospital, Prague* *Tomáš Zima, Charles University Rector, Prague* *Ladislav Dušek, Head of the Institute of Health Information and Statistics of the Czech Republic, Prague*
09:00 – 09:20	ICBD/ICBDSR Update: *Marcia Feldkamp, Chair, Executive Committee*
09:20 – 10:00	**J David Erickson Lecture** Bringing birth defects to the forefront of the global agenda for every woman every child *Salimah Walani, Vice President of Global Programs, March of Dimes*
10:00 – 10:10	**ICBDSR Distinguished Service Award**
10:10 – 10:25	Update from EUROCAT and EUROlinkCAT: *Amanda J Neville, President EUROCAT Association, Centro di Epidemiologia, Università di Ferrara, Italy*
10:25 – 10:40	Update from the NBDPN: *Paul Romitti, Department of Epidemiology, College of Public Health, University of Iowa*
10:40 – 11:10	*Coffee break – Networking*
11:10 – 12:45	**Session I – Oral Communications** – Moderator: Ignacio Zarante **Screening, Prenatal Diagnosis, and Surveillance** Exome sequence and evolving prenatal diagnosis (*Amal Alhashem*) Prenatal diagnosis and prevalence of critical congenital heart disease: An international retrospective cohort study (*Boris Groisman*)

	Multicenter approach to assess newborn hearing screening results in Germany (*Anke Rißmann*) Fetal anomalies non-invasive screening, is serum metabolomic a viable way *(Jacopo Troisi*) Surveillance of congenital anomalies in the Czech Republic: Historical aspects and current status (*Antonin Šípek Jr*) A proposal of data quality indicators for birth defects surveillance (*Boris Groisman*)
12:45 – 14:15	*Lunch*

Monday, October 1, 2018	
14:15 – 15:50	**Session II – Oral Communications** – Moderator: Anke Rißmann **Prevalence** High prevalence of selected birth defects in Ensenada, Baja California, Mexico (*Jorge Rosenthal*) Prevalence of birth defects among immigrants from the Republic of the Marshall Islands: A controversy revisited? (*Wendy Nembhard*) National population-based estimates for selected birth defects, 2010-2014 (*Cara Mai*) Prevalence of birth defects (BD) considered as rare diseases (RD) in Colombia, in a cohort of 9,852 patients with BD in two birth defects surveillance programs (*Claudia Marcela López-Burbano*) Prevalence of gastroschisis and omphalocele in Costa Rica 1996-2014 (*Adriana Benavides Lara*) Association between the congenital abdominal wall defects with early maternal age in the years 2001-2017 and the temporal tendency of the prevalence in the years 2011-2017 in the cities of Bogotá and Cali (*Catherin Tovar Sánchez*)
15:50 – 16:20	*Coffee break – Networking*

16:20 – 17:40	**Session III – Oral Communications** – Moderator: Adriana Benavides Lara **Outcomes** Miscarriages – a lost opportunity (*Margery Morgan*) Trisomy 18 – prevalence and mortality – multi-registry population based analysis (*Nitin Goel*) Trisomy 13 – prevalence and mortality – multi-registry population based analysis (*Nitin Goel*) A retrospective observational analysis of pregnancy outcomes for cases of fetal pericardial effusion over 18 years (*Catherine Stone*) A predictive model of infant mortality for newborns with operated as well as not operated congenital heart defects: A prospective, population-based cohort (EPICARD) study (*Karim Tarabit*)
17:40 – 19:00	**Poster session – Lounge Plzeň**
20:00	*Dinner at Hotel Olšanka (included in the registration fee)*

Tuesday, October 2, 2018	
08:30 – 10:30	**Annual Business Meeting** – First part – *ICBDSR members only*
10:30 – 10:45	*Coffee break*
10:45 – 12:30	**Annual Business Meeting** – Second part – *ICBDSR members only*
12:30 – 13:30	*Lunch*

Tuesday, October 2, 2018	
13:30 – 14:00	ICBDSR Collaborative Projects Updates - Mark Canfield
14:00 – 14:30	ICBDSR New Collaborative Projects - Paul Romitti
14:30 – 15:30	**Session IV – Oral Communications** – Moderator: Cecilia Mellado Sagredo **Risk Factors** Understanding how the concentration of neighborhood advantage and disadvantage affects spina bifida risk among births to non-Hispanic white and Hispanic women, Texas, 1999-2014 (*Mark Canfield*) No detected risk-increase for birth defects after bariatric surgery (*Karin Källén*) Cultural and daily lifestyle influences associated with birth defects in Nigeria (*Olubunmi Lawal-Aiyedun*) Exposure to air pollution and greenness and congenital anomalies (*Wei Luo*)
15:30 – 16:00	*Coffee break*
16:00 – 16:45	**Session IV – Oral Communications** – Moderator: Cecilia Mellado Sagredo **Risk Factors** Maternal vitamin B12 status is associated with risk of cleft lip and cleft palate in Tamil Nadu State, India (*Ron Munger*) Predicted risk of neural tube defect-affected pregnancies exacerbated by vitamin B12 status among non-pregnant women of childbearing age: Belize National Micronutrient Biomarker Survey (BNMS), 2011 (*Jorge Rosenthal*) Shared genomic segments in high-risk multigenerational pedigrees with gastroschisis (*Marcia Feldkamp*)
16:45 – 17:15	**Update on the WBDD –** Eva Bermejo Sánchez and Boris Groisman
18:15	*Dinner in the city centre at Municipal House (personal pay)*

Wednesday, October 3, 2018	
Scientific Session on Rare Diseases Moderators: Professor Milan Macek Jr, Dr. Jiří Horáček, and Dr. Antonín Šípek Jr	
08:30 – 08:40	Introduction and official welcome from Professor Milan Macek Jr Chair of Czech Society of Medical Genetics and Genomics, Prague, Czech Republic
08:40 – 09:20	Rare disease initiatives in the Czech Republic and European Reference Networks 2018: Milan Macek Jr, MD, DSc Department of Biology and Medical Genetics, Charles University Prague, 2nd School of Medicine and University Hospital Motol, Prague, Czech Republic
09:20 – 10:00	Rare diseases: focus on the rarest and the undiagnosed: Bruno Dallapiccola, MD Scientific Directorate, Bambino Gesù Children's Hospital IRCCS, Rome, Italy
10:00 – 10:45	*Coffee break – Networking*
10:45 – 11:15	Screening of pregnancy complications: Pavel Calda, MD, CSc Fetal Medicine Center, General University Hospital and First Medical Faculty, Charles University, Prague Czech Republic
11:15 – 11:40	Non-invasive prenatal testing: where are we now and where are we going?: Martin Hynek, MD Gennet, The Centre for Fetal Medicine and Reproductive Genetics, Prague, Czech Republic
11:40 – 12:05	Preimplantation genetic testing of monogenic diseases by karyomapping: Jakub Horak, PhD Repromeda Biology Park, Brno, Czech Republic
12:05 – 12:35	Neonatal screening – The Czech experience: Viktor Kožich, MD, CSc General University Hospital and Charles University, First Faculty of Medicine, Prague, Czech Republic
12:35 – 14:00	*Lunch*
Classification and Surveillance	
14:00 – 14:20	Classifications and terminology of rare diseases - the Czech translation of Orphanet terms: Miroslav Zvolský, MD Institute of Health Information and Statistics of the Czech Republic, Prague, Czech Republic
14:20 – 14:40	Czech National Registry of Congenital Anomalies – "New" online reporting system and the implementation of rare diseases reporting tools: Jitka Jirova, MSc Institute of Health Information and Statistics of the Czech Republic, Prague
14:40 – 15:10	*Coffee break – Networking*
15:10 – 15:30	Surveillance of rare diseases: The English experience: Mary Bythell, MSc Rare Disease Registration, National Congenital Anomaly and Rare Disease Registration Service-NCARDRS, Public Health England, UK
15:30 – 15:50	Surveillance of rare diseases - the Spanish experience: Eva Bermejo Sánchez, PhD Instituto de Salud Carlos III, Madrid ISCIII, Spain