

PERSONAL INFORMATION **Ingeborg Barisic**

## WORK EXPERIENCE

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- 2016–March 2018 **President of the Expert Council of the Children’s University Hospital Zagreb**  
Children’s University Hospital Zagreb, Medical School University of Zagreb (Croatia)
- 2012–2015 **President of the Scientific and Teaching Board of the Children’s University Hospital Zagreb**  
Children’s University Hospital Zagreb, Medical School University of Zagreb (Croatia)
- 2010–Present **President of the Commission for Drafting and Implementation of a National Programme for Rare Diseases**  
Ministry of Health of the Republic of Croatia (Croatia)
- 2006–Present **Member of the Committee for Paediatrics**  
Ministry of Health of the Republic of Croatia (Croatia)
- 2003–Present **Head of the Referral Centre of the Croatian Ministry of Health for the Surveillance of Congenital Anomalies**  
Children’s University Hospital Zagreb, Medical School University of Zagreb (Croatia)
- 1999–2003 **Head of the Department of Paediatrics**  
Children’s University Hospital Zagreb, Medical School University of Zagreb (Croatia)
- 1997–Present **Editor-in-Chief of the journal Paediatrica Croatica**  
Croatian Pediatric Society, Croatian Medical Association (Croatia)
- 1996–Present **Teaching Professor**  
Medical School University of Zagreb, Faculty of Education and Rehabilitation Sciences University of Zagreb, Faculty of Pharmacy and Biochemistry University of Zagreb (Croatia)
- 1996–2019 **Head of the Department of Medical Genetics and Reproductive Health**  
Children’s University Hospital Zagreb, Medical School University of Zagreb (Croatia)
- September 1979–1995 **Medical doctor, resident in pediatrics, pediatrician**  
Public Health Centre Trnje, Clinical Hospital Centre Zagreb, Children’s University Hospital Zagreb (Croatia)

## EDUCATION AND TRAINING

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- 2004–Present **2010 Full Professor of Paediatrics, 2004 Associate Professor of Pediatrics, 2004 Associate Professor of Medical Genetics**  
Medical School University of Zagreb (Croatia)
- 1999 **Sub-specialisation in Medical Genetics**  
Ministry of Health of the Republic of Croatia (Croatia)

- 1989 **Ph.D.**  
 Medical School University of Zagreb (Croatia)
- 1980–1986 **Specialization in Paediatrics**  
 Clinical Hospital Centre Zagreb, Medical School University of Zagreb (Croatia)
- 1985–1986 **Postgraduate studies in Medical Genetics**  
 Medical School University of Zagreb
- 1981–1982 **Postgraduate studies in Pediatrics**  
 Medical School University of Zagreb (Croatia)
- 1977–1979 **Postgraduate studies in Biomedicine**  
 Medical School University of Zagreb (Croatia)
- 1972–1977 **M.D.**  
 Medical School University of Zagreb (Croatia)

#### ADDITIONAL INFORMATION

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- Expertise**
- Rare paediatric diseases
  - Clinical genetics
  - Treatment of inherited metabolic disorders
  - Orphan drugs
  - Use of drugs during pregnancy
  - Epidemiology of rare syndromes
  - Congenital anomalies

- Publications**
- Scopus  
 145 publications  
 Scopus number of citations 3416  
 H index 30  
 Selected 20 publications
1. Barisic I, Boban L, Akhmedzhanova D, Bergman JEH, Cavero-Carbonell C, Grinfelde I, Materna-Kirylyuk A, Latos-Bieleńska A, Randrianaivo H, Zymak-Zakutnya N, Sansovic I, Lanzoni M, Morris JK. Beckwith Wiedemann syndrome: A population-based study on prevalence, prenatal diagnosis, associated anomalies and survival in Europe. *Eur J Med Genet.* 2018 May 16. pii: S1769-7212(18)30159-9. doi: 10.1016/j.ejmg.2018.05.014
  2. Bergman JEH, Lutke LR, Gans ROB, Addor MC, Barisic I, Cavero-Carbonell C, Game E, Gatt M, Klungsoyr K, Lelong N, Lynch C, Mokoroa O, Nelen V, Neville AJ, Pierini A, Randrianaivo H, Rissmann A, Tucker D, Wiesel A, Dolk H, Loane M, Bakker MK. Beta-Blocker use in pregnancy and risk of specific congenital anomalies: A European case-malformed control study. *Drug Saf.* 2018;41(4):415-427. doi: 10.1007/s40264-017-0627-x.
  3. Ecker A, Mariz S, Naumann-Winter F, Norga K, Barisic I, Girard T, Tomasi P, Mentzer D, Sepodes B. Comparative analysis of the scope of European Union paediatric investigation plans with corresponding orphan designations. *Arch Dis Child.* 2018;103(5):427-430. doi: 10.1136/archdischild-2017-313352.
  4. Dumic KK, Grubic Z, Yuen T, Wilson RC, Kusec V, Barisic I, Stingl K, Sansovic I, Skrabac V, Dumic

- M, New MI. Molecular genetic analysis in 93 patients and 193 family members with Classical Congenital Adrenal Hyperplasia due to 21-hydroxylase deficiency in Croatia. *J Steroid Biochem Mol Biol.* 2017;165(Pt A):51-56. doi: 10.1016/j.jsbmb.2016.03.035
5. Dvorakova L, Vlaskova H, Sarajlija A, Petkovic Ramadza D, Poupetova H, Hrubá E, Hlavata A, Bzduch V, Peskova K, Storkanova G, Kecman B, Djordjevic M, Baric I, Fumic K, Barisic I, Reboun M, Kulhanek J, Zeman J, Magner M. Genotype-phenotype correlation in 44 Czech, Slovak, Croatian and Serbian patients with mucopolysaccharidosis type II. *Clin Genet.* 2016 Nov 24. doi: 10.1111/cge.12927
6. Luteijn JM, Morris JK, Game E, Given J, de Jong-van den Berg L, Addor MC, Bakker M, Barisic I, Gatt M, Klungsoyr K, Latos-Bielenska A, Lelong N, Nelen V, Neville A, O'Mahony M, Pierini A, Tucker D, de Walle H, Wiesel A, Loane M, Dolk H. EUROmediCAT signal detection: a systematic method for identifying potential teratogenic medication. *Br J Clin Pharmacol.* 2016;82:1110-22.
7. Given JE, Loane M, Luteijn JM, Morris JK, de Jong van den Berg LT, Game E, Addor MC, Barisic I, de Walle H, Gatt M, Klungsoyr K, Khoshnood B, Latos-Bielenska A, Nelen V, Neville AJ, O'Mahony M, Pierini A, Tucker D, Wiesel A, Dolk H. EUROmediCAT signal detection: an evaluation of selected congenital anomaly-medication associations. *Br J Clin Pharmacol.* 2016;82: 1094-109.
8. Morris JK, Rankin J, Game E, Loane M, Greenlees R, Addor MC, Arriola L, Barisic I, Bergman JE, Csaky-Szunyogh M, Dias C, Draper ES, Gatt M, Khoshnood B, Klungsoyr K, Kurinczuk JJ, Lynch C, McDonnell R, Nelen V, Neville AJ, O'Mahony MT, Pierini A, Randrianaivo H, Rissmann A, Tucker D, Verellen-Dumoulin C, de Walle HE, Wellesley D, Wiesel A, Dolk H. Prevalence of microcephaly in Europe: population based study. *BMJ.* 2016;354:i4721
9. Dolk H, Wang H, Loane M, Morris J, Game E, Addor MC, Arriola L, Bakker M, Barisic I, Doray B, Gatt M, Kallen K, Khoshnood B, Klungsoyr K, Lahesmaa-Korpinen AM, Latos-Bielenska A, Mejnartowicz JP, Nelen V, Neville A, O'Mahony M, Pierini A, Rißmann A, Tucker D, Wellesley D, Wiesel A, de Jong-van den Berg LT. Lamotrigine use in pregnancy and risk of orofacial cleft and other congenital anomalies. *Neurology.* 2016 May 3;86(18):1716-25
10. Game E, Hansen AV, Morris J, Zaupper L, Addor MC, Barisic I, Gatt M, Lelong N, Klungsoyr K, O'Mahony M, Nelen V, Neville AJ, Pierini A, Tucker D, de Walle H, Wiesel A, Loane M, Dolk H. Use of asthma-medication during pregnancy and risk of specific congenital anomalies –A European case-malformed control study. *J Allergy Clin Immunol.* 136:1496-1502. e7, (2015).
11. Khoshnood B, Loane M, Walle Hd, Arriola L, Addor MC, Barisic I, Beres J, Bianchi F, Dias C, Draper E, Game E, Gatt M, Haeusler M, Klungsoyr K, Latos-Bielenska A, Lynch C, McDonnell B, Nelen V, Neville AJ, O'Mahony MT, Queisser-Luft A, Rankin J, Rissmann A, Ritvanen A, Rounding C, Sipek A, Tucker D, Verellen-Dumoulin C, Wellesley D, Dolk H. Long term trends in prevalence of neural tube defects in Europe: population based study. *BMJ.* 2015;351:h5949.
12. Barisic I, Boban L, Loane M, Game E, Wellesley D, Calzolari E, Dolk H, Addor MC, Bergman JE, Braz P, Draper ES, Haeusler M, Khoshnood B, Klungsoyr K, Pierini A, Queisser-Luft A, Rankin J, Rissmann A, Verellen-Dumoulin C. Meckel-Gruber Syndrome: a population-based study on prevalence, prenatal diagnosis, clinical features, and survival in Europe. *Eur J Hum Genet.* 2015;23:746-52.
13. McGivern MR, Best KE, Rankin J, Wellesley D, Greenlees R, Addor MC, Arriola L, de Walle H, Barisic I, Beres J, Bianchi F, Calzolari E, Doray B, Draper ES, Game E, Gatt M, Haeusler M, Khoshnood B, Klungsoyr K, Latos-Bielenska A, O'Mahony M, Braz P, McDonnell B, Mullaney C, Nelen V, Queisser-Luft A, Randrianaivo H, Rissmann A, Rounding C, Sipek A, Thompson R, Tucker D, Wertelecki W, Martos C. Epidemiology of congenital diaphragmatic hernia in Europe: a register-based study. *Arch Dis Child Fetal Neonatal Ed.* 2015;100:F137-44.
14. Barisic I, Odak L, Loane M, Game E, Wellesley D, Calzolari E, Dolk H, Addor MC, Arriola L, Bergman J, Bianca S, Doray B, Khoshnood B, Klungsoyr K, McDonnell B, Pierini A, Rankin J, Rissmann A, Rounding C, Queisser-Luft A, Scarano G, Tucker D. Prevalence, prenatal diagnosis and clinical features of oculo-auriculo-vertebral spectrum: a registry-based study in Europe. *Eur J Hum Genet.* 2014; 22:1026-33.
15. Wijers C, van Rooij I, Bakker M, Marcelis C, Addor M, Barisic I, Béres J, Bianca S, Bianchi F, Calzolari E, Greenlees R, Lelong N, Latos-Bielenska A, Dias C, McDonnell R, Mullaney C, Nelen V, O'Mahony M, Queisser-Luft A, Rankin J, Zymak-Zakutnia N, de Blaauw I, Roeleveld N, de Walle H. Anorectal malformations and pregnancy-related disorders: a registry-based case-control study in 17 European regions, *BJOG.* 2013;120:1066-74.
16. Barisic I, Odak LJ, Loane M, Game E, Wellesley D, Calzolari E, Dolk H, Addor MC, Arriola L, Bergman J, Bianca S, Boyd PA, Draper ES, Gatt M, Haeusler M, Khoshnood B, Latos-Bielenska A, McDonnell B, Pierini A, Rankin J, Rissmann A, Queisser-Luft A, Verellen-Dumoulin Ch, Stone D, Tenconi R. Fraser syndrome: Epidemiological study in a European population. *Am J Med Genet.* 2013;161A:1012-8.

17. Khoshnood B, Loane M, Garne E, Addor MC, Arriola L, Bakker M, Barisic I, Bianca S, Boyd P, Calzolari E, Doray B, Draper E, Gatt M, Haeusler M, Melve KK, Latos-Bielenska A, McDonnell B, Mullaney C, Nelen V, O'Mahony M, Pierini A, Queisser-Luft A, Randrianaivo H, Rankin J, Rissmann A, Salvador J, Tucker D, Verellen-Dumoulin C, Wellesley D, Zymak-Zakutnya N, Dolk H. Recent decrease in the prevalence of congenital heart defects in Europe. *J Pediatr.* 2013;162:108-13.e2.
18. Garne E, Loane M, Dolk H, Barisic I, Addor MC, Arriola L, Bakker M, Calzolari E, Matias Dias C, Doray B, Gatt M, Melve KK, Nelen V, O'Mahony M, Pierini A, Randrianaivo-Ranjatoelina H, Rankin J, Rissmann A, Tucker D, Verellen-Dumoulin C, Wiesel A. Spectrum of congenital anomalies in pregnancies with pregestational diabetes. *Birth Defects Res A Clin Mol Teratol.* 2012;94:134-40.
19. Jentink J, Loane MA, Dolk H, Barisic I, Garne E, Morris JK, de Jong-van den Berg LT; EUROCAT Antiepileptic Study Working Group. Valproic acid monotherapy in pregnancy and major congenital malformations. *N Engl J Med.* 341:c6581, (2010).
20. Petkovic G, Barisic I. FAS prevalence in a sample of urban schoolchildren in Croatia. *Reprod Toxicol.* 2010;29:237-41, (2010).

IF = 3.137

#### Projects

- 2018 -2. Horizon 2020 project Grant Agreement number: 831390 — ONW — HP-PJ-03-2018
- 2017 - Horizon 2020 project EUROlinkCAT: Establishing a linked European Cohort of Children with Congenital Anomalies; Grant Agreement Number: 733001
- 2017 - COST Action OC-2016-1-208-62 - Neuro-MIG (Neuroepan Network on Brain Malformations)
- Horizon2020 ZIKAPLAN Project. International Committee for Birth Defect Surveillance Tools for Infectious Disease Preparedness (734584)
- Project Grant (HP-PJ-2018) 3rd EU Health Programme Topic: PJ-01-2018 EJP
- 2015-2016 Improving EUROCAT database capacity to serve as source for studies of rare genetic diseases, EU Commission, Contract No CCR.IHCPC443727.X0
- 2013- 2015 FP7 project -EUROmediCAT - Safety of Medication Use in Pregnancy in Relation to Risk of Congenital Malformations, Grant Agreement no 260598
- JA - EUROCAT (European Registration of Congenital Anomalies) – contract with EC DGF4 od 1.01.2011: Grant Agreement no 20102204 (2011-2013)
- EUROPLAN - European Project for Rare Diseases National Plans Development, funded by the European Commission within the EU Program of Community Action in the field of Public Health (2008-2011)
- EPIRARE (European Platform for Rare Disease Registries) co-funded by the European Commission within the EU Program of Community Action in the field of Public Health. (2011-2013)
- "Epidemiology and Genetic Basis of Congenital Anomalies", Croatian Ministry of Science and Technology, project. No. 072-183107-0365 (2007-2014)
- „Genetic basis of Diseases in Children ”- Croatian Ministry of Science Program (2007-2014)
- "Epidemiological, Clinical and Biological Aspects of Birth Defects", Croatian Ministry of Science and Technology (project No. 077-1605) (2002-2007)
- "Molecular Cytogenetics in Diagnostic of Mental Retardation", Technological developmental-research project (program TEST) Croatian Ministry of Science and Technology (TP-01/072-01) (2001-2003)
- " Epidemiological, Clinical and Biological Aspects of Birth Defects", Croatian Ministry of Science and Technology (project No. 072-777) (1999-2002)
- „Genetic, Morphological, Immunological and Clinical Research in Children with Solid Tumors", Croatian Ministry of Science and Technology (project No. 072-333) (1997-2000)
- BIOMED2 "Evaluation of Prenatal Diagnosis of Congenital Anomalies by Fetal Ultrasonographic Examination" (V Contract No BMH4 CT960539) (1996-2002)
- „Medical and Social Evaluation of Prenatal Diagnosis ", Croatian Ministry of Science and Technology (Project No. 301-324) (1992-1997)

#### Memberships

- 2014. Member of Croatian Academy of Medical Sciences
- 2013 - Member of the Orphanet Board and National representative of Orphanet Croatia
- 2013 -2017 Representative of the Republic of Croatia at Commission's Expert Group on Rare Diseases

2011 - 2016 President of EUROCAT (European Network of Population-Based Registries for the Surveillance of Congenital Anomalies) Association  
2009 - Representative of the National Society of Human Genetics at ESHG  
2009 -2018 President of Croatian Society of Human Genetics of the Croatian Medical Association  
2008 - 2018 President of Croatian Society of Rare Diseases of the Croatian Medical Association  
2009 - 2011 Member of American Academy of Medical Genetics  
2008 - 2017 Member of European Association of Science Editors  
1999 - Member of the Board of Croatian Pediatric Society of the Croatian Medical Association  
1999 - 2011 Member of European Cytogeneticists Association  
1998 - Member of European Society of Human Genetics

**Other Relevant Information****Awards:**

2017- Best medical doctor award, Croatian Alliance of Patients with Rare Diseases  
2009 - Main Board Diploma of Croatian Medical Association  
2005 - "Ladislav Rakovac" Award - Croatian Medical Association