

RESEARCH GROUP BACKGROUND AND ACCOMPLISHMENTS

2015-2020

RARE DISEASES

CURRENT MEMBERS OF THE RESEARCH AREA

Research coordinator

Dra. Clara Cavero Carbonell: cavero_cla@gva.es [ORCID](#) (2015-)

Dr. Óscar Zurriaga Llorens: zurriaga_osc@gva.es [ORCID](#) (2008-2011, 2013-2015)

Dra. Carmen Martos Jiménez: martos_car@gva.es (2011-2013)

Researchers

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Past members of the research group

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Tatiana Fernández fernandez_tatroj@gva.es

RECORD OF THE RESEARCH AREA (Period 2015-2020)

GROUP ACTIVITIES

The epidemiology programme for rare diseases (RD) aims to increase knowledge about the distribution and real situations of diseases and their consequences on the population and uses epidemiological methodology in its analytical design facet as well as the implementation of studies and techniques of spatial epidemiology and the study of quality of life. Compiling records and databases as key elements in the development of research in the field of RD, since they allow sufficient sample sizes to be achieved for clinical or epidemiological research.

LINES OF RESEARCH

1. Determination of the prevalence of RD

2. Study of inequalities in RD

3. Analysis of the determinants of RD

CURRENT COLLABORATIONS WITH OTHER RESEARCH GROUPS

Valencian Community:

Alianza en investigación traslacional en Enfermedades Raras de la Comunitat Valenciana.

National:

Equipo Wilson de la Fundació per Amor a l'Art.

CIBERESP

Participación en la acción estratégica proyecto MEDEA: Zurriaga O, Martos Jiménez MC

ORPHANET España:

Miembros del Comité Científico: Zurriaga O, Martos Jiménez MC, Caveró Carbonell C.

HEMACARE

Editora del Manual for Coding and Reporting Haematological Malignancies” elaborado en el marco del proyecto financiado por la Unión Europea “Cancer Registry based Project on Haematologic Malignancies (HAEMACARE)”, 2010: Martos Jiménez MC.

International:

SCIENTIFIC/TECHNICAL RECORD

■ 1. Research projects funded

2019-2023. *ConcePTION: Building an ecosystem for better monitoring and communicating of medication safety in pregnancy and breastfeeding: validated and regulatory endorsed workflows for fast, optimised evidence generation.* Entidad financiadora: Innovative Medicines Initiative (IMI2). Investigadora principal local: Clara Caveró.

2019-2021. *Codification for Rare Diseases - RDCODE. Joint Action.* Entidad financiadora: Third Health Programme (European Commission). Investigadora principal local: Clara Caveró.

2019-2021. *Análisis, determinantes e impacto de la demora diagnóstica en las Enfermedades Raras.* Entidad financiadora: Fondo de Investigación Sanitaria (ISCIII). Investigador principal: Oscar Zurriaga. Investigadora colaboradora: Clara Caveró.

2017-2021. *Establishing a linked European Cohort of Children with Congenital Anomalies (EUROlinkCAT).* Entidad financiadora: Consumers, Health, Agriculture and Food Executive Agency. Investigadora principal local: Clara Caveró.

2017-2018. *“La situación de la Enfermedad de Wilson en España”.* Entidad financiadora: Fundació Per Amor A l'Art. Investigadora principal: Clara Caveró.

2016-2019. *“Rare Cancers — Joint-Action”.* Entidad financiadora: Consumers, Health, Agriculture and Food Executive Agency. Investigadora principal local: Clara Caveró.

2015-2018. *“Promoting Implementation of Recommendations on Policy, Information and Data for Rare Diseases — RD-ACTION”.* Entidad financiadora: Consumers, Health, Agriculture and Food Executive Agency. Investigadora colaboradora: Clara Caveró.

2015-2016. *“Conviviendo con la Enfermedad de Wilson: la visión de pacientes, familiares y profesionales”*. Entidad financiadora: Fundació Per Amor A l'Art. Investigadora principal: Clara Cavero.

2015-2016. *“El síndrome de Stevens-Johnson: identificación de los factores de riesgo en una enfermedad rara”*. Entidad financiadora: FISABIO. Investigador principal: Oscar Zurriaga. Investigadora colaboradora: Clara Cavero.

2012-2015. *“Investigar para prevenir las enfermedades raras pediátricas: Aplicación a las anomalías congénitas cardíacas Raras”*. Entidad financiadora: Fundación GENT per GENT. Investigadora principal: Carmen Martos / Carmen Barona. Investigadora colaboradora: Clara Cavero.

2012-2015. *“Red Española de registros de ER para la Investigación”*. Entidad financiadora: ISCIII. International Rare Diseases Research Consortium.. Investigadora contratada / colaboradora: Clara Cavero.

2. Publications

YEAR 2020

1. van de Putte, R, van Rooij, I, Haanappel, C, Marcelis, C, Brunner, H, Addor, M, Cavero-Carbonell, C, Dias, C, Draper, E, Etxebarriarteun, L, Gatt, M, Khoshnood, B, Kinsner-Ovaskainen, A, Klungsoyr, K, Kurinczuk, J, Latos-Bielenska, A, Luyt, K, O'Mahony, M, Miller, N, Mullaney, C, Nelen, V, Neville, A, Perthus, I, Pierini, A, Randrianaivo, H, Rankin, J, Rissmann, A, Rouget, F, Schaub, B, Tucker, D, Wellesley, D, Wiesel, A, Zymak-Zakutnia, N, Loane, M, Barisic, I, de Walle, H, Bergman, J, Roeleveld, N. Maternal risk factors for the VACTERL association: A EUROCAT case-control study. *Birth Defects Res.* 2020; 112(9): 688 - 698. Available from: www.doi.org/10.1002/bdr2.1686
2. Best, K, Rankin, J, Dolk, H, Loane, M, Haeusler, M, Nelen, V, Verellen-Dumoulin, C, Garne, E, Sayers, G, Mullaney, C, O'Mahony, M, Gatt, M, De Walle, H, Klungsoyr, K, Carolla, O, Cavero-Carbonell, C, Kurinczuk, J, Draper, E, Tucker, D, Wellesley, D, Zymak-Zakutnia, N, Lelong, N, Khoshnood, B. Multilevel analyses of related public health indicators: The European Surveillance of Congenital Anomalies (EUROCAT) Public Health Indicators. *Paediatr. Perinat. Epidemiol.* 2020; 34(2): 122 - 129. Available from: www.doi.org/10.1111/ppe.12655
3. van de Putte, R, van Rooij, I, Marcelis, C, Guo, M, Brunner, H, Addor, M, Cavero-Carbonell, C, Dias, C, Draper, E, Etxebarriarteun, L, Gatt, M, Haeusler, M, Khoshnood, B, Klungsoyr, K, Kurinczuk, J, Lanzoni, M, Latos-Bielenska, A, Luyt, K, O'Mahony, M, Miller, N, Mullaney, C, Nelen, V, Neville, A, Perthus, I, Pierini, A, Randrianaivo, H, Rankin, J, Rissmann, A, Rouget, F, Schaub, B, Tucker, D, Wellesley, D, Wiesel, A, Zymak-Zakutnia, N, Loane, M, Barisic, I, de Walle, H, Roeleveld, N, Bergman, J. Spectrum of congenital anomalies among

VACTERL cases: a EUROCAT population-based study. *Pediatr. Res.* 2020; 87(3): 541 - 549. Available from: www.doi.org/10.1038/s41390-019-0561-y

4. Pastor-García M, Gimeno-Martos S, Zurriaga Ó, Sorlí JV, Cervero-Carbonell C. Congenital heart defects in the Valencian Community 2007-2014: The Population-Based Registry Of Congenital Anomalies. *An Pediatr (Barc)* 2020; 92(1): 13 - 20. Available from: www.doi.org/10.1016/j.anpedi.2018.12.019

YEAR 2019

1. Sinclair, M, McCullough, J, Elliott, D, Latos-Bielenska, A, Braz, P, Cervero-Carbonell, C, Jamry-Dziurla, A, Santos, A, Paramo-Rodriguez, L. Exploring Research Priorities of Parents Who Have Children With Down Syndrome, Cleft Lip With or Without Cleft Palate, Congenital Heart Defects, and Spina Bifida Using ConnectEpeople: A Social Media Coproduction Research Study. *J. Med. Internet Res.* 2019; 21(11): e15847. Available from: www.doi.org/10.2196/15847
2. Santoro, M, Coi, A, Barisic, I, Garne, E, Addor, M, Bergman, J, Bianchi, F, Boban, L, Braz, P, Cervero-Carbonell, C, Gatt, M, Haeusler, M, Kinsner-Ovaskainen, A, Klungsoyr, K, Kurinczuk, J, Lelong, N, Luyt, K, Materna-Kiryluk, A, Mokoroa, O, Mullaney, C, Nelen, V, Neville, A, O'Mahony, M, Perthuis, I, Randrianaivo, H, Rankin, J, Rissmann, A, Rouget, F, Schaub, B, Tucker, D, Wellesley, D, Yevtushok, L, Pierini, A. Epidemiology of Dandy-Walker Malformation in Europe: A EUROCAT Population-Based Registry Study. *Neuroepidemiology* 2019; 53(3-4): 169 - 179. Available from: www.doi.org/10.1159/000501238
3. Cervero Carbonell, C, Moreno Marro, S, Barrachina Bonet, L, Paramo Rodriguez, L, Guardiola Vilarroig, S, Zurriaga, O, Regional Population-Based and Rare Dis Res Inst. Validity of sources of information used for the identification of Wilson's disease in the Registries. *Eur. J. Public Health* 2019; 29. Available from: www.doi.org/
4. Cervero Carbonell, C, Miguel Marco, N, Sabater Gregori, X, Esplugues Cebrian, A. Mesothelioma: a rare cancer in the Valencian Region's Cancer Registry (Spain). *Eur. J. Public Health* 2019; 29. Available from: www.doi.org/
5. Cervero Carbonell, C, Barrachina Bonet, L, Fernandez Rojas, T, Moreno Marro, S, Paramo Rodriguez, L, Guardiola-Vilarroig, S, Zurriaga, O. Tetralogy of Fallot in infants less than one year old in the Valencia Region (Spain). *Eur. J. Public Health* 2019; 29: 615 - 615. Available from: www.doi.org/
6. Torres L, Garcia M, Navarrete E, Notario-Barandiaran L, González S, Zurriaga O, Melchor I and Vioque J. Coffee consumption and mortality from all causes of death, cardiovascular disease and cancer in an elderly Spanish population. *Eur. J. Nutr.* 2019; 58(6): 2439 - 2448. Available from: www.doi.org/10.1007/s00394-018-1796-9
7. Coi, A, Santoro, M, Garne, E, Pierini, A, Addor, M, Alessandri, J, Bergman, J, Bianchi, F, Boban, L, Braz, P, Cervero-Carbonell, C, Gatt, M, Haeusler, M,

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8. Rodriguez, L, Llorens, O, Sanjuan, M, Carbonell, C. Wilson disease: The look of medical staff, patients and family members. *Rev. Esp. Salud Publica* 2019; 93: e201904014. Available from: www.doi.org/
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YEAR 2018

1. Soler-Blasco, R, Mas Pons, R, Barona Vilar, C, Zurriaga, O. Inequities in mental health: admissions for psychosis in public hospitals of the Comunitat Valenciana (2008-2015). *Rev. Esp. Salud Publica* 2018; 92: e201811081. Available from: www.doi.org/
2. Caverro Carbonell, C, Moreno Marro, S, Barrachina Bonet, L, Canet Chaques, I, Paramo Rodriguez, L, Guardiola Vilarroig, S, Zurriaga, O. Wilson's disease in Spain, period 2010-2015. *Eur. J. Public Health* 2018; 28(4): 243 - 243. Available from: www.doi.org/
3. Caverro Carbonell, C, Canet Chaques, I, Moreno Marro, S, Paramo Rodriguez, L, Zurriaga, O. Down Syndrome in infants less than one year old in the Valencia Region (Spain). *Eur. J. Public Health* 2018; 28(4): 458 - 458. Available from: www.doi.org/
4. Caverro Carbonell, C, Canet Chaques, I, Moreno Marro, S, Paramo Rodriguez, L, Zurriaga, O. Congenital anomalies of urinary tract in the Population-based Registry of Valencia Region (Spain). *Eur. J. Public Health* 2018; 28(4): 333 - 333. Available from: www.doi.org/
5. Marcos-Gragera, R, Solans, M, Galceran, J, Fernandez-Delgado, R, Fernandez-Teijeiro, A, Mateos, A, Quiros-Garcia, J, Fuster-Camarena, N, De Castro, V, Sanchez, M, Franch, P, Chirlaque, M, Ardanaz, E, Martos, C, Salmeron, D, Peris-Bonet, R, Spanish Childhood Canc. Childhood and adolescent lymphoma in Spain: incidence and survival trends over 20 years. *Clin Transl Oncol* 2018; 20(10): 1289 - 1301. Available from: www.doi.org/10.1007/s12094-018-1860-1

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7. Barisic, I, Boban, L, Akhmedzhanova, D, Bergman, J, Cavero-Carbonell, C, Grinfelde, I, Materna-Kiryluk, A, Latos-Bielenska, A, Randrianaivo, H, Zymak-Zakutnya, N, Sansovic, I, Lanzoni, M, Morris, J. Beckwith Wiedemann syndrome: A population-based study on prevalence, prenatal diagnosis, associated anomalies and survival in Europe. *Eur. J. Med. Genet.* 2018; 61(9): 499 - 507. Available from: www.doi.org/10.1016/j.ejmg.2018.05.014
8. Bergman JEH, Lutke LR, Gans ROB, Addor MC, Barisic I, Cavero-Carbonell C, Garne 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. Available from: www.doi.org/10.1007/s40264-017-0627-x
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YEAR 2017

1. LOPEZ-BRIONES REVERTE, M, ZURRIAGA LLORENS, Ó, BERNABEU, J, BARONA VILAR, C. Comparative analysis of dietary guidelines for Spain. *Public Health Panorama* 2017; 3(4): 799 - 807. Available from: www.doi.org/
2. Gimeno-Martos, S, Perez-Riera, C, Guardiola-Villarraig, S, Cavero-Carbonell, C. Epidemiology of Imperfect Osteogenesis: a Rare Disease in the Valencia Region. *Rev. Esp. Salud Publica* 2017; 91: UNSP e201711045. Available from: www.doi.org/
3. Pastor-Garcia, M, Gimeno-Martos, S, Paramo-Rodriguez, L, Guardiola-Villarraig, S, Sorli, J, Zurriaga, O, Cavero-Carbonell, C. Congenital heart defects in the East of Spain. *Eur. J. Public Health* 2017; 27(3): 464 - 464. Available from: www.doi.org/
4. Given JE, Loane M, Garne E, Nelen V, Barisic I, Randrianaivo H, Khoshnood B, Wiesel A, Rissmann A, Lynch C, Neville AJ, Pierini A, Bakker M, Klungsoyr K, Latos Bielenska A, Cavero-Carbonell C, Addor MC, Zymak-Zakutnya N, Tucker D, Dolk H. Gastroschisis in Europe - A Case-malformed-Control Study of Medication and Maternal Illness during Pregnancy as Risk Factors. *Paediatr.*

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www.doi.org/10.1111/ppe.12401
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 7. Aguilar-Palacio I, Martinez-Beneito MA, Rabanaque MJ, Borrell C, Cirera L, Daponte A, Domínguez-Berjón MF, Gandarillas A, Gotsens M, Lorenzo-Ruano P, Marí-Dell'Olmo M, Nolasco A, Saez M, Sánchez-Villegas P, Saurina C, Martos C and other MEDEA members. Diabetes mellitus mortality in Spanish cities: Trends and geographical inequalities. *Prim. Care Diabetes* 2017; 11(5): 453 - 460. Available from: www.doi.org/10.1016/j.pcd.2017.05.006
 8. Cavero-Carbonell C, Gimeno-Martos S, Páramo-Rodríguez L, Rabanaque-Hernández MJ, Martos-Jiménez C, Zurriaga Ó. Drugs use in pregnancy in the Valencia Region and the risk of congenital anomalies. *An Pediatr (Barc)* 2017; 87(3): 135 - 142. Available from: www.doi.org/10.1016/j.anpedi.2016.08.003
 9. Cavero-Carbonell C, Gimeno-Martos S, Zurriaga Ó, Rabanaque-Hernández MJ, Martos-Jiménez C. The validity of the Spanish Minimum Basic Data Set to identify congenital anomalies in the Valencian Community (Spain). *Gac. Sanit.* 2017; 31(3): 220 - 226. Available from: www.doi.org/10.1016/j.gaceta.2016.09.014
 10. Boyle B, Garne E, Loane M, Addor MC, Arriola L, Cavero-Carbonell C, Gatt M, Lelong N, Lynch C, Nelen V, Neville AJ, O'Mahony M, Pierini A, Rissmann A, Tucker D, Zymak-Zakutnia N, Dolk H. The changing epidemiology of Ebstein's anomaly and its relationship with maternal mental health conditions: a European registry-based study. *Cardiol. Young* 2017; 27(4): 677 - 685. Available from: www.doi.org/10.1017/S1047951116001025
 11. Cavero-Carbonell C, Vinkel-Hansen A, Rabanque-Hernández MJ, Martos C and Garne E. Fetal Exposure to Montelukast and Congenital Anomalies: A Population Based Study in Denmark. *Birth Defects Res.* 2017; 109(6): 452 - 459. Available from: www.doi.org/10.1002/bdra.23621
 12. Marcos-Gragera R, Galceran J, Martos C, de Munain AL, Vicente-Raneda M, Navarro C, Quirós-García JR, Sánchez MJ, Ardanaz E, Ramos M, Mateos A, Salmerón D, Felipe S and Peris-Bonet R. Incidence and survival time trends for Spanish children and adolescents with leukaemia from 1983 to 2007. *Clin Transl Oncol* 2017; 19(3): 301 - 316. Available from: www.doi.org/10.1007/s12094-016-1531-z

YEAR 2016

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2. Cavero-Carbonell, C, Gras-Colomer, E, Gimeno-Martos, S, Paramo-Rodriguez, L, Amoros, R, Zurriaga, O and Spain-RDR Grp. A national approach to Marfan Syndrome in Spain. *Eur. J. Public Health* 2016; 26. Available from: www.doi.org/
3. Cavero-Carbonell, C, Gimeno-Martos, S, Gras-Colomer, E, Paramo-Rodriguez, L, Alfaro, A, Zurriaga, O. Stevens Johnson Syndrome: identification of the risk factors in a rare disease. *Eur. J. Public Health* 2016; 26: 376 - 376. Available from: www.doi.org/
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9. Cavero-Carbonell C, Gras-Colomer E, Guaita-Calatrava R, López-Briones C, Amorós R, Abaitua I, Posada M, Zurriaga O. Consensus on the criteria needed for creating a rare-disease patient registry. A Delphi study. *J. Public Health* 2016; 38(2): 178 - 186. Available from: www.doi.org/10.1093/pubmed/fdv099
10. Pippias M, Jager KJ, Kramer A, Leivestad T, Sánchez MB, Caskey FJ, Collart F, Couchoud C, Dekker FW, Finne P, Fouque D, Heaf JG, Hemmelder MH, Kramar R, De Meester J, Noordzij M, Palsson R, Pascual J, Zurriaga O, Wanner C, Stel VS. The changing trends and outcomes in renal replacement

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12. Páramo-Rodríguez, L, Mas Pons, R, Caverro-Carbonell, C, Martos-Jiménez, C, Zurriaga, Ó, Barona Vilar, C. An open heart: experiences of the parents of children with congenital heartdisease (vol 29, pg 445, 2015). *Gac. Sanit.* 2016; 30(2): 166 - 166. Available from: www.doi.org/10.1016/j.gaceta.2015.11.001
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YEAR 2015

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5. Participation in education and training programs

Dra. Clara Cavero Carbonell, profesora colaboradora del Grado en Enfermería y de la asignatura de Enfermedades Raras del Grado en Medicina, de la Universitat de València.

Dr. Óscar Zurriaga, profesor Asociado en el Departamento de Medicina Preventiva y Salud Pública, Ciencias de la Alimentación, Toxicología y Medicina Legal. Universitat de València

Dra. Carmen Martos Jiménez, profesora Asociada en el Departamento de Enfermería de la Universitat de València.

Dra. Carmen Martos Jiménez y Dr. Óscar Zurriaga, profesores en el Máster en Salud Pública y Gestión Sanitaria (Universitat de València-ADEIT-Conselleria de Sanitat)

Dra. Carmen Martos Jiménez, profesora en el Master Oficial Inter-Universitario de Ciencias de la Enfermería –MICCE.

Dra. Carmen Martos Jiménez, coordinadora y profesora del curso “La encuesta como técnica de investigación en ciencias de la salud. Elaboración de cuestionarios y tratamiento estadístico de los datos”. Escuela Universitaria de Ciencias de la Salud de Zaragoza, 27/09/2010 – 05/10/2010.

5. Doctoral theses

- Fecha: 28/02/2020
- Título: Migración y salud: diferencias en mortalidad perinatal..
- Doctorando: María del Rocío Zurriaga Carda
- Director/es: Dr. Oscar Zurriaga Llorens, Dr. José Vicente Sorlí Guerola
- Universidad: Universitat de València
- Calificación: Sobresaliente *cum laude*

- Fecha: 30/06/2017
- Título: Anomalías congénitas: distribución de la prevalencia y factores asociados.
- Doctorando: Clara Cavero Carbonell
- Director/es: Dra. Carmen Martos Jiménez, Dra. María José Rabanaque Hernández
- Universidad: Universidad de Zaragoza
- Calificación: Sobresaliente *cum laude*

- Fecha: 13/01/2017
- Título: Mortalidad materna y morbilidad materna grave en la Comunitat Valenciana (2006-2010).
- Doctorando: Rosa Mas Pons
- Director/es: Dr. Francisco Bolumar Montrull, Dra. Carmen Barona Vilar, Dr. Oscar Zurriaga Llorens
- Universidad: Universidad de Alcalá de Henares
- Calificación: Sobresaliente *cum laude*

- Fecha: 09/01/2017

- Título:

Construcción del concepto de alimentación saludable a través de la publicidad.
España, 1960-2013.

- Doctorando: María del Carmen López Briones

- Director/es: Dra. Carmen Barona Vilar, Dr. Oscar Zurriaga Llorens

- Universidad: Universidad de Alicante

- Calificación: Sobresaliente *cum laude*