

## References

1. Reller MD, Strickland MJ, Riehle-Colarusso T, Mahle WT, Correa A. Prevalence of congenital heart defects in metropolitan Atlanta, 1998-2005. *J Pediatr.* 2008 Dec;153(6):807-13. doi: 10.1016/j.jpeds.2008.05.059. Epub 2008 Jul 26. PMID: 18657826; PMCID: PMC2613036.
2. Oster ME, Lee KA, Honein MA, Riehle-Colarusso T, Shin M, Correa A. Temporal trends in survival among infants with critical congenital heart defects. *Pediatrics.* 2013 May;131(5):e1502-8. doi: 10.1542/peds.2012-3435. Epub 2013 Apr 22. PMID: 23610203; PMCID: PMC4471949.
3. Arth AC, Tinker SC, Simeone RM, Ailes EC, Cragan JD, Grosse SD. Inpatient Hospitalization Costs Associated with Birth Defects Among Persons of All Ages - United States, 2013. *MMWR Morb Mortal Wkly Rep.* 2017 Jan 20;66(2):41-46. doi: 10.15585/mmwr.mm6602a1. PMID: 28103210; PMCID: PMC5657658.
4. Gilboa SM, Devine OJ, Kucik JE, Oster ME, Riehle-Colarusso T, Nembhard WN, Xu P, Correa A, Jenkins K, Marelli AJ. Congenital Heart Defects in the United States: Estimating the Magnitude of the Affected Population in 2010. *Circulation.* 2016 Jul 12;134(2):101-9. doi: 10.1161/CIRCULATIONAHA.115.019307. Epub 2016 Jul 5. PMID: 27382105; PMCID: PMC4942347.
5. Oster ME, Lee KA, Honein MA, Riehle-Colarusso T, Shin M, Correa A. Temporal trends in survival among infants with critical congenital heart defects. *Pediatrics.* 2013 May;131(5):e1502-8. doi: 10.1542/peds.2012-3435. Epub 2013 Apr 22. PMID: 23610203; PMCID: PMC4471949.
6. Farr SL, Klewer SE, Nembhard WN, Alter C, Downing KF, Andrews JG, Collins RT, Glidewell J, Benavides A, Goudie A, Riehle-Colarusso T, Overman L, Riser AP, Oster ME. Rationale and design of CH STRONG: Congenital Heart Survey To Recognize Outcomes, Needs, and well-being. *Am Heart J.* 2020 Mar;221:106-113. doi: 10.1016/j.ahj.2019.12.021. Epub 2020 Jan 9. PMID: 31986287
7. Oster ME, Riser AP, Andrews JG, Bolin EH, Galindo MK, Nembhard WN, Rose CE, Farr SL. Comorbidities Among Young Adults with Congenital Heart Defects: Results from the Congenital Heart Survey To Recognize Outcomes, Needs, and well-being - Arizona, Arkansas, and Metropolitan Atlanta, 2016-2019. *MMWR Morb Mortal Wkly Rep.* 2021 Feb 12;70(6):197-201. doi: 10.15585/mmwr.mm7006a3. PMID: 33571179; PMCID: PMC7877580.
8. Downing KF, Oster ME, Klewer SE, Rose CE, Nembhard WN, Andrews JG, Farr SL. Disability Among Young Adults With Congenital Heart Defects: Congenital Heart Survey to Recognize Outcomes, Needs, and Well-Being 2016-2019. *J Am Heart Assoc.* 2021 Nov 2;10(21):e022440. doi: 10.1161/JAHA.121.022440. Epub 2021 Oct 20. PMID: 34666499; PMCID: PMC8751822.

9. Farr SL, Downing KF, Goudie A, Klewer SE, Andrews JG, Oster ME. Advance Care Directives Among a Population-Based Sample of Young Adults with Congenital Heart Defects, CH STRONG, 2016-2019. *Pediatr Cardiol*. 2021 Dec;42(8):1775-1784. doi: 10.1007/s00246-021-02663-5. Epub 2021 Jun 23. PMID: 34164699.
10. Broughton A, Riehle-Colarusso T, Nehl E, Riser AP, Farr SL. Preventive care and medical homes among US children with heart conditions. *Cardiol Young*. 2021 Jan;31(1):114-120. doi: 10.1017/S1047951120003443. Epub 2020 Nov 9. PMID: 33161934.
11. Farr SL, Downing KF, Riehle-Colarusso T, Abarbanell G. Functional limitations and educational needs among children and adolescents with heart disease. *Congenit Heart Dis*. 2018 Jul;13(4):633-639. doi: 10.1111/chd.12621. Epub 2018 Jul 22. PMID: 30033554; PMCID: PMC6266870.
12. Downing KF, Oster ME, Farr SL. Preparing adolescents with heart problems for transition to adult care, 2009-2010 National Survey of Children with Special Health Care Needs. *Congenit Heart Dis*. 2017 Jul;12(4):497-506. doi: 10.1111/chd.12476. Epub 2017 May 19. PMID: 28523852; PMCID: PMC5605904.
13. McClung N, Glidewell J, Farr SL. Financial burdens and mental health needs in families of children with congenital heart disease. *Congenit Heart Dis*. 2018 Jul;13(4):554-562. doi: 10.1111/chd.12605. Epub 2018 Apr 6. PMID: 29624879; PMCID: PMC6105538.
14. Razzaghi H, Oster M, Reefhuis J. Long-term outcomes in children with congenital heart disease: National Health Interview Survey. *J Pediatr*. 2015 Jan;166(1):119-24. doi: 10.1016/j.jpeds.2014.09.006. Epub 2014 Oct 8. PMID: 25304924; PMCID: PMC4378575.
15. Yu, Julie, and Harris Cooper. "A Quantitative Review of Research Design Effects on Response Rates to Questionnaires." *Journal of Marketing Research*, vol. 20, no. 1, 1983, pp. 36–44, <https://doi.org/10.2307/3151410>. Accessed 5 Apr. 2022.