

Curriculum Vitae
Amy Verstappen, MEd, MGH

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Education

2019 Masters in Global Health

ISGlobal, University of Barcelona
Barcelona, Spain

1989 Masters of Education

Lesley College, Cambridge, MA

1983 B.S. Sociology-Anthropology

Swarthmore College, Swarthmore, PA

Positions Held

2017 – Present Founder and Outgoing President, Global Alliance for Rheumatic and Congenital Hearts, Philadelphia, PA

2001 - 2013 President and CEO, Adult Congenital Heart Association, Philadelphia, PA

Appointments Held

2010 – 2013 Steering Committee Member, Congenital Heart Public Health Consortium

2005 - 2013 Member, ACHD Working Group, American College of Cardiology

2007- 2013 Member, Joint Council on Congenital Heart Disease

2008 - 2010 Member, ACHD Training and Subspecialty Accreditation Writing Group

2007- 2010 Founding Chair, National Congenital Heart Coalition

2004 - 2005 Member, NHLBI Working Group on Research Priorities in Adult Congenital Cardiac Disease

2002- 2005 Advisory Board, International Society for Adult Congenital Heart Disease

Peer-reviewed publications

Ross S, Verstappen A. The Role of Congenital Heart Disease Patient Organizations in Advocacy, Resources, and Support Across the Lifespan. CJC Pediatr Congenit Heart Dis. 2023 Sep

Zheleva B, Verstappen A, Overman DM, Ahmad F, Ali SKM, Al Halees ZY, Atallah JG, Badhwar IE, Baker-Smith C, Balestrini M, Basken A, Bassuk JS, Benson L, Capelli H, Carollo S, Chowdhury D, Çiçek MS, Cohen MI, Cooper DS, Deanfield JE, Dearani J, Del Valle B, Dodds KM, Du J, Edwin F, Ekure E, Fatema NN, Gomanju A, Hasan B, Henry L, Hugo-Hamman C, Iyer KS, Jatene MB, Jenkins KJ, Karamlou T, Karl TR, Kirklin JK, Kreutzer C, Kumar RK, Lopez KN, Macedo AP, Marino BS, Marwali EM, Meijboom FJ, Mattos SS, Najm H, Newlin D, Novick WM, Qureshi SSA, Rahmat B, Raylman R, Saltik IL, Sable C, Sandoval N, Saxena A, Scanlan E, Sholler GF, Smith J, St Louis JD, Tchervenkov CI, Tiong KG, Vida V, Vosloo S, Weinstein DJD, Wilkinson JL, Zuhlke L, Jacobs JP. Advocacy at the Eighth World Congress of Pediatric Cardiology and Cardiac Surgery. Cardiol Young. 2023 Aug

Vervoort D, Jin H, Edwin F, Kumar RK, Malik M, Tapaua N, Verstappen A, Hasan BS. Global Access to Comprehensive Care for Paediatric and Congenital Heart Disease. CJC Pediatr Congenit Heart Dis. 2023 Oct

Hasan BS, Bhatti A, Mohsin S, Barach P, Ahmed E, Ali S, Amanullah M, Ansong A, Banu T, Beaton A, Bolman RM 3rd, Borim BC, Breinholt JP, Callus E, Caputo M, Cardarelli M, Hernandez TC, Croti UA, Ejigu YM, Fenton K, Gomanju A, Harahsheh AS, Hesslein P, Hugo-Hamman C, Khan S, Kpodonu J, Kumar RK, Jenkins KJ, Lakhoo K, Malik M, Nichani S, Novick WM, Overman D, Quenot AP, Patton Bolman C, Pearson D, Raju V, Ross S, Sandoval NF, Sholler G, Sharma R, Shidhika F, Sivalingam S, Verstappen A, Vervoort D, Zühlke LJ, Zheleva B. Recommendations for developing effective and safe paediatric and congenital heart disease services in low-income and middle-income countries: a public health framework. *BMJ Glob Health*. 2023 May

Hummel K, Whittaker S, Sillett N, Basken A, Berghammer M, Chalela T, Chauhan J, Garcia LA, Hasan B, Jenkins K, Ladak LA, Madsen N, March A, Pearson D, Schwartz SM, St Louis JD, van Beynum I, Verstappen A, Williams R, Zheleva B, Hom L, Martin GR. Development of an international standard set of clinical and patient-reported outcomes for children and adults with congenital heart disease: a report from the International Consortium for Health Outcomes Measurement Congenital Heart Disease Working Group. *Eur Heart J Qual Care Clin Outcomes*. 2021 Jul

Ladak LA, Pearson D, Jenkins K, Amanullah M, Ahmad W, Schmeck KD, Verstappen A, Hasan BS. **Adult congenital cardiac life-long needs evaluation in a low-middle income country**, Pakistan. *J Pak Med Assoc*. 2020 Dec;

Moons P, Bratt EL, De Backer J, Goossens E, Hornung T, Tutarel O, Zühlke L, Araujo JJ, Callus E, Gabriel H, Shahid N, Sliwa K, Verstappen A, Yang HL, Thomet C. **Transition to adulthood and transfer to adult care of adolescents with congenital heart disease: a global consensus statement of the ESC Association of Cardiovascular Nursing and Allied Professions (ACNAP), the ESC Working Group on Adult Congenital Heart Disease (WG ACHD), the Association for European Paediatric and Congenital Cardiology (AEPC), the Pan-African Society of Cardiology (PASCAR), the Asia-Pacific Pediatric Cardiac Society (APPCS), the Inter-American Society of Cardiology (IASC), the Cardiac Society of Australia and New Zealand (CSANZ), the International Society for Adult Congenital Heart Disease (ISACHD), the World Heart Federation (WHF), the European Congenital Heart Disease Organisation (ECHDO), and the Global Alliance for Rheumatic and Congenital Hearts (Global ARCH)**. *Eur Heart J*. 2021 Nov

Hummel K, Whittaker S, Sillett N, Basken A, Berghammer M, Chalela T, Chauhan J, Garcia LA, Hasan B, Jenkins K, Ladak LA, Madsen N, March A, Pearson D, Schwartz SM, St Louis JD, van Beynum I, Verstappen A, Williams R, Zheleva B, Hom L, Martin GR. **Development of an international standard set of clinical and patient-reported outcomes for children and adults with congenital heart disease: a report from the International Consortium for Health Outcomes Measurement Congenital Heart Disease Working Group**. *Eur Heart J Qual Care Clin Outcomes*. 2021 Jul

Riehle-Colarusso TJ, Bergersen L, Broberg CS, Cassell CH, Gray DT, Grosse SD, Jacobs JP, Jacobs ML, Kirby RS, Kochilas L, Krishnaswamy A, Marelli A, Pasquali SK, Wood T, Oster ME; **Congenital Heart Public Health Consortium. Databases for Congenital Heart Defect Public Health Studies Across the Lifespan**. *J Am Heart Assoc*. 2016 Oct 26

Rozenblum R, Gianola A, Ionescu-Iltu R, Verstappen A, Landzberg M, Gurvitz M, Jenkins K, Bates DW, Marelli AJ. **Clinicians' perspectives on patient satisfaction in adult congenital heart disease clinics--a dimension of health care quality whose time has come**. *Congenit Heart Dis*. 2015 Mar-Apr;10(2):128-36. doi: 10.1111/chd.12190. Epub 2014 Jun 17. PMID: 24934436.

Broberg CS, Mitchell J, Rehel S, Grant A, Gianola A, Beninato P, Winter C, Verstappen A, Valente AM, Weiss J, Zaidi A, Earing MG, Cook S, Daniels C, Webb G, Khairy P, Marelli A, Gurvitz MZ, Sahn DJ. **Electronic medical record integration with a database for adult congenital heart disease: Early experience and progress in automating multicenter data collection**. *Int J Cardiol*. 2015 Oct 1;196:178-82. doi: 10.1016/j.ijcard.2015.05.140. Epub 2015 May 27. PMID: 26142077.

Fernandes SM, Verstappen A, Ackerman K, Adams EE, Barton C, Breitingner P, Crumb S, Dummer K, Harada K, Khairy P, Landzberg MJ, Linstead-Goldsmith R, Meadows AK, Nieves JA, Saidi A, Takahashi M, Zhou J, Ziniel S, Williams R; Adult Congenital Heart Association; Adult Congenital Cardiac Care Associate Research Network. **Parental knowledge regarding**

lifelong congenital cardiac care. *Pediatrics.* 2011 Dec;128(6):e1489-95. doi: 10.1542/peds.2010-3068. Epub 2011 Nov 28. PMID: 22123874.

Cotts T, Khairy P, Opotowsky AR, John AS, Valente AM, Zaidi AN, Cook SC, Aboulhosn J, Ting JG, Gurvitz M, Landzberg MJ, **Verstappen A**, Kay J, Earing M, Franklin W, Kogon B, Broberg CS; Alliance for Adult Research in Congenital Cardiology (AARCC). **Clinical research priorities in adult congenital heart disease.** *Int J Cardiol.* 2014 Feb 15;171(3):351-60.

Valente AM, Landzberg MJ, Gianola A, Harmon AJ, Cook S, Ting JG, Stout K, Kuehl K, Khairy P, Kay JD, Earing M, Houser L, Broberg C, Milliren C, Opotowsky AR, Webb G, **Verstappen A**, Gurvitz M; Alliance for Adult Research in Congenital Cardiology (AARCC) Investigators; Adult Congenital Heart Association (ACHA). **Improving heart disease knowledge and research participation in adults with congenital heart disease (the Health, Education and Access Research Trial: HEART-ACHD).** *Int J Cardiol.* 2013 Oct 9;168(4):3236-40.

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Prevalence and Predictors of Gaps In Care Among Adult Congenital Heart Disease Patients
(The Health, Education and Access Research Trial: HEART-ACHD). *J Am Coll Cardiol* 2013

Fernandes SM, Verstappen A, Ackerman K, Adams EE, Barton C, Breiting P, Crumb S, Dummer K, Harada K, Khairy P, Landzberg MJ, Linstead-Goldsmith R, Meadows AK, Nieves J, Saidi A, Takahasi M, Zhou J, Ziniel S, Williams R on behalf of the Adult Congenital Heart Association and the Adult Congenital Cardiac Care Associate Research Group. **Parental Knowledge Regarding Lifelong Congenital Cardiac Care.** *Pediatrics* ePub Dec 1, 2011; 128 (6).

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Hilderson D, Saidi AS, Van Deyk K, Verstappen A, Kovacs AH, Fernandes SM, Canobbio MM, Fleck D, Meadows A, Linstead R, Moons P. **Attitude toward and current practice of transfer and transition of adolescents with congenital heart disease in the United States of America and Europe.** *Pediatr Cardiol.* 2009 Aug;30(6):786-93. Epub 2009 Apr 14. PMID: 19365651.

Williams RG, Pearson GD, Barst RJ, Child JS, del Nido P, Gersony WM, Kuehl KS, Landzberg MJ, Myerson M, Neish SR, Sahn DJ, Verstappen A, Warnes CA, Webb CL; National Heart, Lung, and Blood Institute Working Group on research in adult congenital heart disease. **Report of the National Heart, Lung, and Blood Institute Working Group on research in adult congenital heart disease.** *J Am Coll Cardiol.* 2006 Feb 21;47(4):701-7.

Verstappen A, Pearson D, Kovacs AH. **Adult congenital heart disease: the patient's perspective.** *Cardiol Clin.* 2006 Nov;24(4):515-29

Knauth A, Verstappen A, Reiss J, Webb GD. **Transition and transfer from pediatric to adult care of the young adult with complex congenital heart disease.** *Cardiol Clin.* 2006 Nov;24(4):619-29,

Book Chapters:

Cannobio M, Moons P, Nickolaus M, Verstappen A. **Nursing in Adult Congenital Heart Disease. In Cardiac Nursing: A Companion to Braunwald's Heart Disease** by Debra K. Moser, Barbara Riegel. WB Saunders Co Ltd. May, 2007.

Perloff JK, Verstappen A. **National and International Scope. In Congenital Heart Disease in Adults** by Joseph K. Perloff, John Child, Jamil Aboulhosen. Third Edition. WB Saunders Co Ltd. August, 2008.