January 22, 2019

Gift Tee
Acting Director, Division of Practitioner Services
Center for Medicare Management
Centers for Medicare & Medicaid Services
Mail Stop C4-01-26
7500 Security Boulevard
Baltimore, MD 21244

Dear Mr. Tee:

By way of this letter, the American College of Cardiology (ACC) writes to request establishment of a new Medicare specialty code for Adult Congenital Heart Disease (ACHD) specialists. This submission aligns with the requirements enumerated in Chapter 26 of the Medicare Claims Processing Manual.

The American College of Cardiology envisions a world where innovation and knowledge optimize cardiovascular care and outcomes. As the professional home for the entire cardiovascular care team, the mission of the College and its more than 52,000 members is to transform cardiovascular care and to improve heart health. The ACC bestows credentials upon cardiovascular professionals who meet stringent qualifications and leads in the formation of health policy, standards and guidelines. The College also provides professional medical education, disseminates cardiovascular research through its world-renowned JACC Journals, operates national registries to measure and improve care, and offers cardiovascular accreditation to hospitals and institutions. For more, visit acc.org.

Rationale for recognition through a new specialty code

Documentation and tracking needs exist for an adult congenital cardiology specialty code. An ACHD cardiologist is typically asked to provide consultation and ongoing care by referral from the general cardiologist in the academic and community setting and pediatric cardiologist transitioning from pediatric to adult care. The majority of academic centers (pediatric and adult) require an ACHD consult service and 24/7 call schedule due to the distinct sub-specialization of the ACHD cardiologist. Without a specifically identified adult congenital cardiology specialty code, ACHD cardiologist are evaluated and measured as either general internal medicine or pediatric cardiologists and unable to separate quality measures and outcomes important for improving care, and unable to bill as a
separate subspecialty. Lack of a specialty code for adult congenital cardiology affects the growth and development of the field, the development of ACHD programs within academic institutions and hence providing access to high quality patient care. With a specific adult congenital cardiology specialty code, ACHD cardiologists will be able to document and track the differences in patient population and care provided in comparison to other cardiologists.

Markedly different from the dominant parent specialty

ACHD cardiologists have a unique and special expertise in caring for young adults and adults born with congenital heart defects. Specifically, ACHD cardiologists fill an important role in the continuum of specialized care for those born with a heart defect and have survived to adulthood. Currently, approximately 1% of every infant live birth has a congenital heart defect—it the most common birth defect. Pediatric cardiologists are skilled at caring for infants and children with CHD. Improved survival at earlier ages has led to an exponential growth of CHD patients reaching adulthood. The CDC estimates there are now more adults than children with CHD by a 65/35 margin with 2/3rds surviving with moderate and complex CHD. There are at least 1.5 million adults living with CHD in the US.

However, after reaching adulthood morbidity and mortality are substantial higher than expected from residual cardiac anatomic abnormalities, arrhythmias, and physiologic changes that lead to heart failure. Pediatric cardiologists are not trained to care for adults and internal medicine cardiologist do not receive CHD training during their cardiovascular fellowship. This well-recognized gap in the care of CHD patients has led to patients being lost to specialized care, higher than expected hospitalization rates, health care utilization 2-5 times higher than age matched cohorts, and earlier than expected mortality. Data from outside the US has demonstrated that overall survival improves when ACHD patients are cared for by ACHD cardiologists within ACHD programs.¹

Completion of specialized training and certification

The American Board of Internal Medicine (ABIM) and the American Board of Pediatrics approved ACHD as a separate subspecialty in 2012. There are now ACHD board certified cardiologists distributed geographically throughout the US. The Accreditation Council for Graduate Medical Education (ACGME) approved ACHD subspecialty training under ABIM cardiovascular training in 2015. Under the guidance of ACGME, a unique approach was approved to allow either pediatric cardiologists or internal medicine cardiologists a pathway to ACGME ACHD fellowship training, recognizing the uniqueness of this specific training beyond traditional cardiology training and need to grow the subspecialty for this underserved population. Importantly, ACGME requires 24 months of ACHD training beyond 36 months of either internal medicine cardiology or pediatric cardiology training. The 24 months of ACHD training is the longest duration

required for any of the cardiovascular subspecialty fellowship—interventional, heart failure or electrophysiology cardiovascular fellowships, all of which have CMS specialty designations. The 24 months additional training demonstrates the extensive skills and expertise required for ACHD sub-specialization beyond general cardiology.

Medicare volume

As there currently is no separation between ACHD cardiologist and general cardiologists, analyzing specific claim data for ACHD is challenging. We are able to analyze specific CHD diagnoses from national inpatient services and cross reference age to determine broadly the population and resource utilization for ACHD and the Medicare population. We have known that for the past decade the population is aging and is utilizing substantial CMS resources that we expect will continue to grow.

Data from the National Inpatient Sample (longitudinal hospital-based inpatient data under HCUP - the Healthcare and Utilization Project from AHRQ - Agency for Healthcare Research and Quality demonstrates the significant volume of care provided by ACHD specialists to ACHD patients.

**Figure 1: Annual ACHD U.S. hospital admissions** (years 2003-2014) segregated by disease severity. The data demonstrates there has been a steady rise in ACHD admissions across disease severities. Over the 12 years recorded hospital admissions for all disease severities rose to greater than 250,000 in 2014.
Figure 2: Annual Medicare charges per ACHD patient admission years 2003-2014 segregated by disease severity. Hospital charges per patient admission have doubled from 2003 to 2014.

Figure 3: Annual aggregate Medicare charges for ACHD hospital care (years 2003-2014). Annual inpatient charges for all ACHD diagnoses have quadrupled from 2003 to 2014.
External recognition of specialty

The American College of Cardiology/American Heart Association published the first ACHD Care Guidelines published in 2008, to guide the general cardiologist caring for ACHD patients. In 2012, the American Board of Internal Medicine, the American Board of Pediatrics, and the American Board of Medical Specialties Certified Subspecialty recognized ACHD as a separate and distinct cardiovascular subspecialty. The Accreditation Council for Graduate Medical Education (ACGME) approved ACHD as a certified training program in 2015. With the growth and development of the subspecialty, the ACC/AHA published an entire revision of the 2008 care guidelines in 2018 that is directed more heavily toward the ACHD cardiologist. With 10 years of data since the original guidelines, the updated 2018 guidelines provide a new classification system for ACHD patients and lesion specific algorithms and follow-up tables.

ACHD is recognized by the National Heart, Lung and Blood Institute (NHLBI). The NHLBI ACHD Working Group publishes reports recognizing their agenda and work. The Centers for Disease Control (CDC) recognizes ACHD and consults with research specialists in the field collaborating to develop research and education priorities.

The Adult Congenital Heart Association (ACHA) is a patient advocacy organization with the mission to improve and extend the lives of the millions born with heart defects through education, advocacy and promotion of research. Founded in 1998, it is now the largest ACHD advocacy organization in the world with over 50,000 patient and provider members. In 2015, ACHA, with its medical providers, developed ACHD program accreditation. Through an application, rigorous criteria and a site visit, 25 ACHD programs have been approved to date as Comprehensive Care Centers in the US. The accreditation program is vetted and endorsed by 20 health care and patient organizations and societies, recognizing the uniqueness and importance for specialized ACHD care. The American College of Cardiology and the American Heart Association have endorsed
A new provider taxonomy code for ACHD, 207RA0002X, was added by the National Uniform Claim Committee on July 1, 2018. It was effective October 1, 2018. It recognizes, “A physician who specializes in the care and treatment of adults with congenital heart disease. Adult congenital heart disease (ACHD) physicians are trained to understand the complexities of congenital heart disease, anatomy, physiology, surgical repairs, and long-term complications and use that to manage ACHD with acquired heart disease, including heart failure, arrhythmias, and pulmonary hypertension.”