Top Ten Things To Know
Chronic Heart Failure in Congenital Heart Disease

1. The prevalence of pediatric and adult congenital heart disease (CHD) is increasing as a result of the successes of surgical and interventional treatment and advanced diagnostic techniques.

2. More than 1 million adults are living with CHD in the United States. The most common congenital disorder diagnosed in newborns is structural heart disease.

3. This statement reviews the literature relevant to chronic heart failure (HF) in CHD, and identifies knowledge gaps from pediatric to adult patients with CHD and HF.

4. This document looks at the mechanisms and treatment of myocardial dysfunction, recognizing that HF symptoms may be caused by other underlying abnormalities.

5. Any CHD patient with HF symptoms should be evaluated in detail by an experienced CHD cardiologist.

6. Newborns with complex CHD now have approximately a 90% survival rate; over 95% who live past their first year of life remain alive at age 16.

7. Statistics from the paper:
   - “Adults with CHD are also living longer, with the overall median age at death increasing from 37 years in 2002 to 57 years in 2007.
   - Even more striking is the change in mortality for patients with CHD of great complexity in whom the median age at death has increased from 2 years prior to 1995 to almost 25 years currently.
   - Over one fourth of CHD diagnoses are made after infancy.”

8. HF continues to be a common complication of CHD.
   - “HF was the major cause of late death (>30 days) in children after pediatric cardiac surgery, contributing to 27% of the deaths and occurring at a median age of 5.2 years.
   - HF is the leading cause of death in adults with CHD as well, described as 26% of all deaths in a national registry of over 8000 adults with CHD.”

9. Challenges for HF management in CHD patients include “the wide range of ages at which HF occurs, the heterogeneity of the underlying anatomy and surgical repairs, the wide spectrum of HF causes, the lack of validated biomarkers for disease progression, the lack of reliable risk predictors or surrogate endpoints, and the paucity of evidence demonstrating treatment efficacy.”

10. Palliative care is a valuable part of care in these patients.