Considerations for Advanced Heart Failure Consultation in Congenital Heart Disease (CHD) Patients: *Guidance for primary cardiologists*

ADVANCED CARDIAC THERAPIES IMPROVING OUTCOMES NETWORK

HARMONIZED PROTOCOL

BACKGROUND

To aid in and standardize decision-making on timing of referral of CHD patients for advanced heart failure consultation with the aim of harmonizing referral practices, improving timely referral and facilitating collaborative care to enhance patient outcomes.

Patient population: Two ventricle CHD patients

Considerations for referral[1,2]

Symptoms

1) NYHA Class 3-4 symptoms attributable to heart disease (pulmonary or systemic ventricle) despite optimal medical or surgical therapy

AND/OR

Clinical events

1) > 2 admissions for heart failure in a 6-month period without a reversible cause
2) Any admission for heart failure that requires continuous inotropic therapy (even if only transiently required)
3) Life-threatening arrhythmias refractory to medical or surgical therapy

AND/OR

Evidence of end-organ dysfunction attributable to heart disease defined as:

1) Progressive liver disease attributable heart disease-related congestion despite optimal therapy
2) Patients with pulmonary hypertension with a potential risk of developing fixed elevation in pulmonary vascular resistance which might preclude future heart transplantation[3]
3) Adult patients with progressive cachexia or pediatric patients with refractory growth failure attributable to heart disease despite optimal therapy
4) Patients with progressive cardiorenal syndrome or with refractory hyponatremia (<130mmol/L) attributable to heart failure despite optimal therapy

[1] In adult patients, referral should be to a combined program including both ACHD and advanced heart failure providers

[2] In patients with a high probability of prolonged waiting list time such as those with high levels of allosensitization earlier referral should be considered.

[3] Particular monitoring of patients with a systemic morphologic RV

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Disclaimer: *The ACTION network is focused on quality improvement efforts such as harmonizing best practice protocols, disseminating them among institutions, and helping centers to improve care practices at the local level. This referral guideline was developed as a consensus tool for general cardiologists. The information in the guideline is based on center practices, individual opinions, experiences, and, where available, published literature. Providers & centers may choose to adapt this protocol to include in their center-specific protocols with reference to ACTION with the understanding that this is meant as a guideline and not as standard of care. (Revised: 02/06/2020)*