Top Ten Things To Know
Neurodevelopmental Outcomes in Children With Congenital Heart Disease: Evaluation and Management

1. There is a greater risk of developmental disorders and developmental delay for children with congenital heart disease (CHD).

2. Statistics:
   - Estimated prevalence of CHD - 9 per 1000 live births
   - Survival into adulthood for children diagnosed with CHD - 85%
   - Complexity of disease impacts survival rates
   - Overall increase in survival rates - also includes the most complex defects
   - Adults with complex CHD likely outnumber children

3. This scientific statement uses data from a review of existing literature to provide recommendations to optimize neurodevelopmental outcomes for pediatric congenital heart disease (CHD) patients. It is intended for medical providers in the medical home who care for patients with CHD.

4. The 'medical home' refers to “the optimal setting for family-centered care coordination.”

5. Neurodevelopmental and behavioral impairment has a distinct pattern in complex CHD:
   - mild cognitive impairment
   - impaired social interaction
   - impairments in core communication skills

6. In addition to an algorithm for monitoring neurodevelopmental outcomes in high risk CHD patients, this paper contains an algorithm for surveillance, screening, evaluation and management of developmental disorders or disabilities (DD).

7. The categories of pediatric CHD patients who are at high risk for developmental disorders or disabilities are identified in Table 3.

8. The Individuals With Disabilities Education Act requires that early identification programs are in place in every state.

9. Surveillance, screening, evaluation, and reevaluation continue to be key steps for the transition into adulthood, and includes referrals for higher education and/or vocational counseling.

10. Regular reevaluation throughout childhood can identify important neurodevelopmental deficits and provide opportunities for timely and appropriate interventions and therapies.