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2018 Newburger-Bellinger Award

**Neurodevelopmental Perspectives: The Scientist, The Physician, The National Advocate,
The Humble Traveler**

- In the past decade alone, research has progressed from developing a tool to effectively assess health-related quality of life (HRQOL) in the pediatric cardiac population to establishing the critical impact of neurodevelopmental and psychosocial morbidity on HRQOL in patients with CHD and to actively exploring how to prevent and treat the consequences of neurodevelopmental morbidity and nurture resilience to improve HRQOL.
- Advocacy plays a critical role in our ability to advance patient care and improve outcomes. To advance our efforts in patient care, we must prove that supporting preventative and interventional services to improve ND and psychosocial outcomes is 'good policy' for the improvement of overall population health. The Cardiac Neurodevelopmental Outcome Collaborative grew out of the initial efforts to produce guidelines for effective neurodevelopmental evaluation and management, and has now grown significantly from the first meeting in Boston in 2012 into a rapidly growing network of cardiac neurodevelopmental outcome programs that span the United States and are spreading internationally. In addition to continuing to support this growth, successful advocacy must also harness our collective efforts through collaboration with other networks, organizations, and stakeholders as put forth by the vision statement of Cardiac Networks United.
- Finally, Dr. Marino spoke about the future direction of CNOC, including the formation of six working groups with support of an NHLBI R13 grant, who are working to produce a white paper that will guide future research and scientific innovation. Working groups are aimed at Fetal Brain Development and Neuroprotection; Surgical/Perioperative Neuroprotection and Neurodevelopment; Characterization of Neurodevelopmental and Psychosocial Outcomes; Neurodevelopmental and Psychosocial Intervention; Family Stress and Coping; and Neurodevelopmental Education, Outreach and Advocacy.

Key themes:

1. Need for interventions to nurture resilience and optimize executive function
2. Advocacy is the key to advancing patient care and improving outcomes. Individually through school liaison and coordination of care and nationally through organizations such as CNOC and Cardiac Networks United
3. NHLBI R13 grant is an example of how we can work together to highlight and prioritize the CNOC research agenda