

Neuropsychology Cardiac Follow-up Clinic at Kennedy Krieger Institute

Who We Are

The Neuropsychology Cardiac Follow-up Clinic at Kennedy Krieger Institute is one of the few clinics in the country that focuses on evaluating the developmental, attention, learning, emotional, and behavioral concerns of children with congenital heart issues.

Congenital heart defects are the most common birth defect, affecting about nine out of every 1,000 babies born in the U.S. Thanks to advances in cardiac care, 85 percent of these infants now survive into adulthood. As more and more children survive heart surgery, physicians and researchers have found that nearly half of children born with heart problems go on to have developmental and learning issues.

As a result, the American Heart Association has created new guidelines for children born with heart defects to have early and ongoing screenings for developmental delays and disorders, which could include difficulty in school, behavior issues, poor social skills, or language and speech problems. *(See reverse side for American Heart Association guidelines.)*

Who We Serve

The clinic provides specialized neuropsychological care to children and adolescents who were born with congenital heart defects.

Our Team

The clinic works in coordination with pediatric cardiologists and pediatric cardiac surgeons from the child's hospital to provide neuropsychological follow-up care and services for their patients. The clinic is staffed by pediatric neuropsychologists from the Department of Neuropsychology at Kennedy Krieger Institute. Individuals are referred to additional specialists, as needed, including physical therapists, speech and language pathologists, occupational therapists, educational specialists, and behavioral psychologists.



Our Approach

Our experienced specialists are specifically trained to recognize and treat conditions that affect how a child thinks, learns, and behaves. We work closely with families, schools, early intervention specialists, and other medical providers to:

- Carefully evaluate a wide range of cognitive and behavioral skills;
- Help determine appropriate early intervention services and assist with academic planning;
- Share with parents and caregivers information and strategies for improved outcomes for their child's development and behavior;
- Provide parents feedback, with recommendations for intervention and treatment options; and
- Monitor progress through comprehensive neuropsychological assessment services through adolescence.

We are all born with great potential.
Shouldn't we all have the chance to achieve it?



Kennedy Krieger Institute
UNLOCKING POTENTIAL

For more information, visit kennedykrieger.org or call 888-554-2080.

American Heart Association Guidelines

The following guidelines were developed by the American Heart Association (AHA) in 2012 for children with congenital heart disease:

- **All children** with congenital heart conditions should undergo standardized neurodevelopmental screening at 9 months, 18 months, 24 months, 30 months, and 48 months. These screenings can be performed by the child's pediatrician.
- **Children classified as "high risk"*** should additionally undergo a comprehensive neurodevelopmental/ neuropsychological evaluation between 12 and 24 months to identify concerns as early as possible, which can help improve developmental outcomes and ensure that patients reach their full potential. Updated evaluations are recommended between 3 and 5 years of age and again between 11 and 12 years of age, or more frequently if suggested by the child's team.
- **Children with any concerns** on their regular screenings should also undergo a comprehensive evaluation at the ages suggested above.

** The 2012 AHA Scientific Statement classifies the following groups as "high risk" for developmental disorders or disabilities:*

- Neonates or infants requiring open heart surgery (cyanotic and acyanotic types) or who have hypoplastic left heart syndrome, interrupted aortic arch, pulmonary atresia with intact ventricular septum, truncus arteriosus, total anomalous pulmonary venous connection, transposition of the great arteries, tetralogy of Fallot, or pulmonary atresia
- Children with other cyanotic heart lesions not requiring open heart surgery during the neonatal or infant period, for example, tetralogy of Fallot, tetralogy of Fallot with shunt without use of cardiopulmonary bypass, or Epstein anomaly
- Any combination of congenital heart disease and the following comorbidities:
 - Prematurity (less than 37 weeks)
 - Developmental delay recognized in infancy
 - Suspected genetic abnormality or syndrome associated with developmental disorders
 - History of mechanical support (extracorporeal membrane oxygenation or ventricular assist device use)

- Heart transplantation
- Cardiopulmonary resuscitation at any point
- Prolonged hospitalization (post-operative length of stay greater than two weeks in the hospital)
- Perioperative seizures related to congenital heart disease surgery
- Significant abnormalities on neuroimaging or microcephaly
- Other conditions determined at the discretion of the medical home provider

Contact Information

Neuropsychology Cardiac Follow-up Clinic

For more information or to schedule an appointment, please call 443-923-9400, or toll-free at 888-554-2080.

TTY: 443-923-2645 or Maryland Relay 711
kennedykrieger.org

Physicians & Healthcare Professionals

To make a referral, call our Physician Referral Line at 443-923-9403.

To make a referral online, visit
neuropsychologyintake.kennedykrieger.org

Clinic Location:

1750 E. Fairmount Avenue
Baltimore, MD 21231

Marino et al., (2012) Outcomes in Children with Congenital Heart Disease Evaluation and Management. *Circulation*, 126, 1143-1172.

Kennedy Krieger Institute recognizes and respects the rights of patients and their families and treats them with courtesy and dignity. Care is provided in a manner that preserves cultural, psychosocial, spiritual and personal values, beliefs, and preferences. We encourage patients and families to become active partners in their care by asking questions, requesting resources, and advocating for the services and support they need.



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