



Neurodevelopment & CHD

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Neurodevelopmental Care

Provides patients and their families with the assessment, treatment and training resources they need from infancy throughout the school years to ensure that children enjoy the highest potential for developmental, cognitive and quality of life success!

CHD & Development

- Babies with congenital heart disease, specifically those who undergo heart surgery in their first year of life, are at risk for neurodevelopmental delays that may affect behavioral and cognitive abilities.
- In the first year of life, fine and gross motor skills are closely monitored. In early childhood, learning, behavioral, and attentional concerns may be present. These developmental needs are sometimes nuanced or difficult to predict.
- Periodic developmental surveillance, screening, evaluation, and reevaluation throughout childhood may enhance identification of significant deficits, allowing for appropriate therapies and education to enhance later academic, behavioral, psychosocial, and adaptive functioning.

When taking care of your child with CHD, we are taking care of more than just the heart!

In the hospital...

A Developmental Care Framework

- Balancing specialized medical care with other aspects of newborn and infant care
- Supporting your baby's physical, psychological, and emotional development in the hospital setting
- Minimizing short- and long-term developmental complications
- Supporting you as parent in the ICU



Neurodevelopmental Rounds

- Occur weekly at bedside – Thursdays at 1pm
- Multidisciplinary team – Behavioral Health, PT, OT, Nursing, Child Life, ND Program Manager, Social Work
- As your child grows, you will see a developmental poster in your room to help with communication of your child’s developmental goals to all staff and caregivers
- Neurodevelopmental rounding with a multidisciplinary team allows for -
 - Discussion with you and the team regarding your child’s developmental goals
 - Gives an opportunity to evaluate and optimize your child’s environment
 - May enhance parent-infant communication and relationships and parenting in the ICU
 - Eases the transition home!

Neurodevelopmental follow-up
following discharge...

Developmental Surveillance

- While your child is inpatient:
 - Therapeutic support and evaluation from PT, OT, Speech
 - Social Work, Child Life, Music and Art Therapy
 - Standardized developmental evaluations with Developmental Psychologist
- Following discharge
 - At Children’s Hospital of Pittsburgh -
 - Neonatal Developmental Follow-up Clinic – infancy and early childhood
 - Neuropsychology – ages 4 and up
 - Child Development Unit (CDU)
 - In the home & outpatient -
 - Early Intervention – ages 0-3
 - Occupational Therapy
 - Speech Therapy
 - Physical Therapy
 - Additional therapeutic services: Developmental, Vision, Nutrition, etc.
 - Outpatient Therapy as needed - OT, PT or Speech

CHP Neonatal Developmental Follow Up Clinic

- Your first appointment is **tele** and **1-2 months following your child's discharge home** from the hospital. Your child will be scheduled prior to discharge
- Your child will then follow with our team through 2-3 years of age, with appointments up to every 6 months. Check-ins throughout early childhood may be scheduled.
- Your developmental team –
 - **Developmental psychologist** - completes a standardized developmental assessment. As your child grows, additional social-emotional and behavioral assessments and ASD screening will be completed as well.
 - **Physical therapy** - also present for your first visit for completion of a neuromotor assessment.
- Provide developmental guidance and support and assist you with any needed referrals for appropriate services including: Early Intervention, subspecialty medical clinics, and continued follow-up after graduation from the developmental clinic



Early Intervention

- **Early intervention (EI)** is a system of services that *helps babies and toddlers with developmental delays or disabilities*. EI focuses on helping eligible babies and toddlers learn the basic and brand-new skills during the first three years of life, such as:
 - *physical* (reaching, rolling, crawling, and walking)
 - *cognitive* (thinking, learning, solving problems)
 - *communication* (talking, listening, understanding)
 - *social/emotional* (playing, feeling secure and happy)
 - *self-help* (eating, dressing)
- Coordinated through your county. Referral placed for you at discharge from the hospital. For more information –
 - In Pennsylvania, call 1-800-692-7288
 - In West Virginia, call (304) 558-5388
 - In Ohio, call 1-800-755-4769

Developmental Surveillance

Please reach out with any developmental questions or concerns at any point for support during your pregnancy, early hospitalizations, and following discharge in early childhood or beyond!

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Developmental Psychologist

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