CARDIAC NEURODEVELOPMENTAL OUTCOMES PROGRAM

Please Join Us
Saturday May 12th
Children’s National Medical Center
1111 Michigan Ave NW
Washington DC 20010

For
THE CARDIAC NEURODEVELOPMENTAL CONNECTION: CRITICAL INFORMATION FOR PARENTS OF CHD WARRIORS

Featuring Mary Donofrio, MD, Jacqueline Sanz, Ph.D., ABPP-CN,
Michael Mintz, Psy.D, Wanda Rankin, M.Ed, Melissa Duva, RN

9:15 - 10:00
Mother’s Day Breakfast/Coffee
Mini-Atrium (2nd Floor beyond Cafeteria)

10:00 - 12:00 pm
Lectures and Q&A
Auditorium (2nd Floor by Cafeteria)
Empowering Families Through Support and Education
Each year in the U.S., about 40,000 families will hear these words:

YOUR BABY HAS A CONGENITAL HEART DEFECT.
Mended *Little* Hearts Is There

❤️ Mended *Little* Hearts is the largest CHD peer-to-peer support network in the world

❤️ Mended *Little* Hearts works Nationally and in Communities, currently 83 Chapters, to provide peer-to-peer support, education, awareness and connect families with needed resources.

❤️ Mended *Little* Hearts volunteers provide direct support to families through its Accredited Visiting Program and delivering 5,000 Bravery Bags annually.
Hope, Help, Healing

ONLINE CONNECTIONS

❤️ Mended *Little* Hearts volunteers support families and patients through Internet and phone outreach as well as by providing Web resources.

❤️ These are ways to get support:

• Join Parent Matching
• Contact your local Mended *Little* Hearts group
  ▪ Facebook: Mended *Little* Hearts National Organization
  ▪ (FB) MLH CHD Chat
  ▪ (FB) CHD Chat for Teens & Young Adults
  ▪ (FB) Mended Little Hearts Angels *closed group for Angel parents and siblings
  ▪ Twitter: @MLH_CHD
  ▪ Instagram: mendedlittleheartsnational
Hope, Help, Healing

CHD AWARENESS INITIATIVES

Most people are unaware that congenital heart defects (CHDs) are the most common birth defects in the United States. Mended Little Hearts has national and local CHD Awareness Initiatives so people have vital information and can get the support they need.

HEALTH EDUCATION TO COMMUNITIES

Congenital heart disease professionals in the community provide helpful information at Mended Little Hearts group meetings, through workshops, seminars and at health fairs.
Washington DC Chapter
Topics for Educational Talks

• Nutrition and Feeding. Is your CHD child a fussy eater? Did he/she have a feeding tube or port? Learn more about challenges CHD kids may have with nutrition and food and how to address them.

• Social Behavior. Does your CHD child have impulse control or other behavior issues? Does he/she seem anxious in certain social situations? Either at home, school or during play? Learn more about the connections between CHD and behavior development.

• Learning. You know your CHD child is bright, but he/she doesn’t seem to demonstrate this at school. Whether your child avoids reading, has trouble with penmanship, or can’t remember his/her multiplications tables, there could be a connection to her CHD.
Washington DC Chapter
Topics for Educational Talks

• **CHD & Family/Partner/Marriage Relationships.** Is your family is stressed a lot – a CHD child requires a lot of extra attention and management and it is can take a toll on families and relationships. Learn coping strategies to help you and yours.

• **Accessing Resources.** CHD is life long. Learn how to access a range of resources. Topics may include education, social and financial assistance programs. Learn about advocacy and CHD research organizations.

• **Medical Anxiety/Post-Traumatic Medical Stress.** Does your CHD child now have a medical phobia of doctors, needles, going to the hospital? Do you worry about how to talk to your child about CHD in an age appropriate way that sets them up for success rather than a life of fear? Learn strategies to help your child with medical anxiety and post-traumatic medical stress.
THANK YOU FOR JOINING US TODAY!
Neurodevelopment and Brain Injury in CHD: What We Know, What We Can Do

Mary T. Donofrio MD, FAAP, FACC, FASE
Professor of Pediatrics
Director of the Fetal Heart Program
Co-Director of Cardiac Neurodevelopmental Outcome Program
Neurodevelopmental Abnormalities in CHD

- The Problem......

Adapted from Wernovsky, 2006

Marino BS, Circulation 2012
Congenital Heart Disease and Outcome: Timeline of Injury

- **Genetic factors**
- **Compromise at delivery**
- **Surgery**
  - CPB/Circulatory arrest
- **Chronic cyanosis**
  - Cardiac dysfunction
  - Arrhythmias
- **Compromise in utero**
- **Preoperative compromise**
- **Postoperative hypotension/hypoxia**
Fetal Ultrasound
Fetal MRI
Advanced Fetal Brain MRI

Fetal studies (Limperopoulos, 2010)
• Delay in brain development in the 3rd trimester in fetuses with CHD

Newborn studies (Miller, 2007, Licht 2009, and Andropoulos, 2010)
• Delay in brain development estimated to be ~5 weeks in TGA and HLHS
• Delay associated with both pre and postoperative brain injury
What can we do???
Modifiable Factors to Improve Outcome: Prenatal Diagnosis

♥ Brain MRI study in newborns with single ventricles or TGA
  • Brain injury less in those with prenatal dx (24 vs 48%)
  • More rapid brain development in those with prenatal dx

Peyvandi S, 2016
Modifiable Factors to Improve Outcome: Maternal Stress

❤ Maternal stress

- High in moms carrying fetuses with CHD
  - 2V CHD - ~50% with anxiety
  - SV CHD - ~50-75% with anxiety

- Fetal brain MRI findings
  - Maternal stress associated with smaller hippocampus in fetuses with specific 2V heart defects
    - Hippocampus is a part of the brain for memory, emotions, and motivation

Wu Y, SPR 2015
Modifiable Factors to Improve Outcome: Fetal Intervention

❤ Fetuses with aortic valve stenosis (evolving HLHS)
  - Blood flow to the brain is abnormal
  - Fetal catheter intervention to open the aortic valve
    - No change in flow after fetal intervention

McElhinney DB, 2010
Modifiable Factors to Improve Outcome: Maternal Oxygen Therapy

♥ Fetuses with HLHS
- Blood flow to the brain abnormal
- While giving oxygen to mom
  - Blood flow to the brain becomes more normal
  - Response dependent on gestational age (not before the third trimester)

Szwast A, 2010
What about me?
Neurodevelopmental Outcomes in Children With Congenital Heart Disease: Evaluation and Management

A Scientific Statement From the American Heart Association

This statement has been approved by the American Academy of Pediatrics.

Bradley S. Marino, MD, MPP, MSCE, FAHA, Co-Chair; Paul H. Lipkin, MD;
Jane W. Newburger, MD, MPH, FAHA; Georgina Peacock, MD, MPH; Marsha Gerdes, PhD;
J. William Gaynor, MD; Kathleen A. Mussatto, PhD, RN; Karen Uzark, PhD, CNP, FAHA;
Caren S. Goldberg, MD, MS; Walter H. Johnson, Jr, MD; Jennifer Li, MD;
Sabrina E. Smith, MD, PhD; David C. Bellinger, PhD; William T. Mahle, MD, FAHA, Co-Chair; on
behalf of the American Heart Association Congenital Heart Defects Committee of the Council on
Cardiovascular Disease in the Young, Council on Cardiovascular Nursing, and Stroke Council

Circulation 2012
Neurodevelopmental Abnormalities in CHD Guidelines for Care

• Mostly all newborns with significant CHD are at risk
  – Neonates/infants requiring open heart surgery in the first year
  – Children with cyanotic CHD (blue babies)
  – Children with CHD and other risk factors
    • Prematurity, developmental delay, genetic abnormality
    • ECMO, heart transplant, CPR, prolonged hospitalization
    • Seizures, brain abnormality on MRI, microcephaly

• Guidelines suggest interval surveillance
  • Infant- 0-1 year
  • Toddler- 1-3.5 years
  • Preschool- 3.5-5 years
  • Adolescence-6-18 years
The CANDO Program

Cardiac Neurodevelopmental Outcome Program
Maximizing Your Child’s Potential for a Bright Future
CANDO Program Roadmap

CANDO PROGRAM ROAD MAP

WHILE IN THE HOSPITAL

DEVELOPMENTAL ROUNDS

CHILD DEVELOPMENT EVALUATION

NEUROLOGY EVALUATION

WHEN YOU GO HOME

6-9 month old visit

12-18 month old visit

2 year visit

3 year visit

4-6 years
  School Readiness Assessment

11-12 years
  Middle School Transition

14-16 years
  High School Visits

CHILD DEVELOPMENT EVALUATION

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CHILD DEVELOPMENT EVALUATION

NEUROPSYCHOLOGICAL EVALUATION

NEUROPSYCHOLOGICAL EVALUATION

NEUROPSYCHOLOGICAL EVALUATION

NEUROLOGY EVALUATION

NEUROLOGY EVALUATION

NEUROLOGY EVALUATION
DEVELOPMENT PLAN
at Children’s National Health System

Ways to Help my Child’s Neurodevelopment

Infancy

Around their first birthday

Toddlerhood

❤ Promote “self-regulatory” routines, such as settling to sleep independently (without the help of a person or bottle) & staying seated for meals.
❤ Language: help your child follow along with a story. See if they can point to pictures in a book or point to body parts on request. Send them on errands to get/take/put/give familiar objects.
❤ Play time: provide simple toys that promote language & pretend play (like a baby doll & related objects). Limit exposure to TV, tablets, phones (too much screen time is associated with language delays & attention problems).

One of the best ways to care of your baby and support his/her development is to take care of yourself! Here are some ideas that you can do to take care of you!

*Contact your social worker if you think you need help managing anxiety or stress related to your babies heart surgery or heart condition.*

❤ Get plenty of rest, take a little time away from the hospital floor!
❤ Physical activity such as walking, yoga or exercise
❤ Eat a well-balanced diet
❤ Spend time with loved ones or friends
Summary

❤️ Alterations in blood flow to the brain in fetuses with CHD are associated with abnormalities in brain structure suggesting that delayed fetal brain maturation impacts neurodevelopment in CHD

❤️ Modifiable factors that may improve ND outcome

- Planned deliveries as late in gestation as possible
- Planned delivery room and neonatal care to minimize hemodynamic compromise
- Maternal treatment of stress and anxiety
- Fetal treatment strategies to improve brain blood flow
Thank you
Neurodevelopment in Infants & Toddlers with Congenital Heart Defects

Michael Mintz, Psy.D.
Associate director, Child Development Clinic
Developmental specialist, CANDO Program
Children’s National Health System
Overview

• Common challenges for CHD kids in early childhood

• What is Executive Functioning?
  - what does EF look like in infancy/toddlerhood?

• Common treatment recommendations
What we do...

• **Child Development Clinic**
  • as part of the CANDO Program
  • Evaluate children ages birth to 3 ½ years of age

• Comprehensive developmental evaluation
  • Bayley Scales of Infant & Toddler Development (BSID-III)
  • Vineland Adaptive Behavior Scales

• Comprehensive developmental interview
  • Emphasis on home-based routines (feeding, sleeping, etc)
Differentiating between domains

• Gross motor development as ‘the most visible delay’
• Parents’ concerns: walking & talking

• Examples:
  • 12-month-old who doesn’t crawl
  • 24-month-old who doesn’t talk
Domains

• “Cognitive”
  • Nonverbal problem-solving/Play skills
• Language
  • Receptive language
  • Expressive language
  • Social communication
• Motor
  • Gross motor
  • Fine motor
Domains (cont.)

- Adaptive functioning
  - Home-based routines (feeding, sleeping, dressing, toileting)
- Social functioning
  - Attachment to parents
  - Relationships with peers
  - Social/emotional development
- Executive functioning
  - Attention, activity level, impulsivity, etc.
Executive Functioning

• Executive function and self-regulation skills are the mental processes that enable us to plan, focus attention, remember instructions, and ‘juggle multiple tasks’ successfully.

• ‘Air traffic control system at a busy airport”... the brain needs this skill set to filter distractions, prioritize tasks, set and achieve goals, and control impulses.
Executive Functioning

- **Working memory** governs our ability to retain and manipulate distinct pieces of information over short periods of time.

- **Mental flexibility** helps us to sustain or shift attention in response to different demands or to apply different rules in different settings.

- **Self-control** enables us to set priorities and resist impulsive actions or responses.
Executive Functioning in Infants & Toddlers

• Sustained attention
  • Focus on a specific task (stay seated for meals)

• Impulse control
  • Inhibit a thought/desire, maintain attention despite it

• Frustration tolerance
  • Persist on difficult task

• Self-regulation
Self-Regulation

• Emotional regulation
  • Recovery when upset (without reliance on immature techniques)
• Settling to sleep
  • Without bottle/rocking; back to sleep after midnight wakings
• Sitting for meals (vs. distracted force-feeding)
  • Sustaining interest/attention in meals
Self-regulation -> Exec. Fx

• Self-regulatory skills, as cultivated in infancy, develop into executive functioning skills in childhood

• Attention/self-regulation/executive functioning as the foundation of learning
Social development

• Self-regulatory skills develop hand-in-hand with social skills
• Soothing in early infancy: oral and tactile
• Soothing in later infancy: transitioning to social forms of soothing
  • Attention to language
  • Attachment to parents as a secure base
Treatment: Starting with the Parents

• Parents’ concerns & goals
  • Medical goals as a priority
  • *Catching up* versus *making progress*

• Quality of life
  • Having “a happy kid”
  • Joy in the parent-child relationship
Formal treatment

• Early intervention services (Infants & Toddlers)
  • Physical therapy
  • Speech therapy
  • Occupational therapy
  • Special instruction
• Special education preschool
  • Child Find
  • Inclusion versus more intensive
Common treatment recommendations

- Receptive language development
- Social communication skills
  - Gestures, eye contact, etc.
- Play skills
  - Hand use & sustained attention
“Treatment” Suggestions

- Home-based routines affecting self-regulation
  - Bedtime (settling to sleep independently)
  - Mealtime (staying seated for meals)
  - Playtime (toys that promote attention; one toy at a time)
- Soothing
  - Social modes of soothing
  - Sensory modes of soothing
    - Bottle or food
    - Screentime quiets the body by overstimulating the brain
Eat, Play, Love (handout)

• Eat: mealtime as ‘social time’
  • Food only at the table

• Play: locomotor, object-oriented, & social
  • Sensory -> Functional -> Social -> Pretend
  • Playdates versus overstimulating ‘group-a-thons’

• Love: joy in the parent-child relationship
  • Encouraging social forms of regulating
Thank you! And Happy Mother’s Day!

Michael Mintz, Psy.D.
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Developmental specialist, CANDO Program

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Neurodevelopmental Outcomes in Congenital Heart Disease

Jacqueline Sanz, PhD, ABPP-CN
Neuropsychologist
CANDO Program Co-Director
Co-Chair, Cardiac Neurodevelopmental Outcome Collaborative (CNOCC)
CHD and the Brain

- CHD Changes the way the brain develops, even in utero
- More susceptible to injury
Figure 1. Factors that affect variability in developmental and neuropsychological outcomes for children and adolescents with CHD. ECMO: extracorporeal membrane oxygenation.
- Socioeconomic status
- Parent education
- Male sex
- Family stress and anxiety
Cassidy et al., 2017

Pre-Operative

- Preterm birth
- Early term birth
- Low birthweight
- Prenatal diagnosis
- Genetics
Peri-Operative

- Brain dysmaturity
- Medical instability
- Cerebral oxygenation
- Acidosis/hematocrit
- Cardiopulmonary bypass time
- Circulatory arrest time
- Anesthesia
- ECMO
- Length of hospital stay
- Neurological abnormalities/insults (e.g., stroke, seizures)

Cassidy et al., 2017
Current Cardiac Function

- Oxygen saturation
- Aortic obstruction/astresia
- Oxygen intake during exercise

Cassidy et al., 2017
What are possible outcomes?

• Wide range of outcomes
• Early speech/motor/feeding – may resolve
• Common problem areas school age + (even in the absence of early delays):
  • Attention/Executive Skills
  • Visual-spatial/Visual Motor/Fine Motor
  • Higher order language
  • Social Skills
  • Academics
What is Executive Function?

• Set of behaviors responsible for purposeful, goal directed activity. It is used to organize and direct cognitive activity, emotional responses, and overt behavior.

• It’s not the “know how,” but “how you do it”

• **Inhibitory Control, Working Memory, Cognitive Flexibility** are the core components, which build into planning, organization, problem solving, and integration of information.
Core Executive Skills

- Inhibitory control
- Working memory
- Flexibility
Commonly Observed Diagnoses

- Increased incidence of
  - ADHD (up to 53% in single ventricle patients)
  - Higher rates of remedial services, grade retention, tutoring, special education services – 30-50% receiving services
    - Thus we believe higher incidence of learning d/o
    - Caveat – this is likely an underestimate, as studies often find that those who qualify for services are not receiving them.
  - Autism Spectrum Disorder – estimates range from 2 to 4-5 X increase in diagnosis.
  - Anxiety Disorders (up to 35% in single ventricle CHD)
Improving the Outcome

CANDO in Action
Monitor/Evaluate

- Evaluate at key points in a child’s development – Neurodevelopmental Stress Points:

1) “Growth Spurts” – where new skills emerge, or leaps in development occur

2) Stressful transitions – where there will be a marked increase in expectations around them.
Growth Spurts

• Infants/Toddlers: Rapidly acquiring mobility, communication skills, basics of language (thus more frequent monitoring)

• Age 4-5: emerging executive skills like self-regulation, social skills like understanding your perspective v others. More complexity in language.

• 6-8: More abstract thinking, concept formation, social skills and problem solving

• Pre-Teen Years, then again in high school/young adulthood: rapid growth in executive skills, complex thinking
“Stress Points”

• Kindergarten Entry: Need to sit still, attend, self-direct for short periods of time, take care of self (e.g., bathroom, dressing/hygiene, eating), employ basic social problem solving.

• 3rd Grade: Basic academics to Applied academics, more self-direction

• 6th Grade: Managing multiple teachers and demands, more complex/long-term assignments

• High School: Workload increases, demands on independence increase, social demands increase

• Adulthood: More completely independent, in charge of finances/medical care, long term educational/career planning
Treatment Plans at Each Stage

Therapies
(speech, OT, PT, psychotherapy, executive skills coaching, tutoring)

Accommodations/Supports
(How does your child best learn? How can we put supports into the environment?)

Collaboration with Schools
(Additional educational assessments, 504 plans, IEPs)
Our goal is to change the story

Early mild speech delay, poor feeding

Trouble acquiring letter/sound relationships, trouble sitting in circle time

Reading slow and clunky, has trouble with comprehension
Trouble organizing/tracking work

He’s been through so much, give him time.

He’s a C ish student, average I guess? Why is schoolwork so hard? He’s getting anxious and sad.

Early intervention – he’ll catch up!

Maybe an evaluation?
Our goal is to change the story

- Early mild speech delay, poor feeding
- K is great, but, trouble sitting in circle time
- Trouble organizing/ tracking work
- Reading comprehension is tough
- Reading is tough, but he’s getting A’s and so proud.

- Early intervention – then come back and we’ll monitor
- 504 plan + therapy
- Add some EF Coaching and resource

- Pre-k/K
- Elementary
- Middle/HS
That said....

• Though “earlier is better,” it is NEVER too late to evaluate or treat problems.

• Trajectories can change at any point.

• For example, interventions to improve Executive Function exist at various age ranges.
There are Interventions Across The Lifespan

- Computerized Cognitive Training
- Physical Activity
- School Curricula/Add Ons
- Cognitive Behavioral Therapy or “coaching”
  - Therapies can be tailored to specific skills or pushed into schools/communities

Diamond & Ling 2016; Diamond 2012; Cannon et al 2011; Kenworthy et al 2013
What do we know about Improving EF?

1. Those who most need it, improve most
2. Transfer effects from EF training are narrow
3. EF needs to be challenged throughout training
4. Repeated practice is key
5. Once practice ends, benefits diminish (use it or lose it)
6. Reason for improvement may not be what you think
   1. E.g., CogMed: Mentorship?
7. Improvement depends on how an activity is done (e.g., exercise needs to be done with cognitive components)
8. Outcome measures need to test limits of EF

Diamond & Ling 2016; Diamond 2012
Programs also need to support ability to handle stressors, improve health, feel belonging

from Diamond 2012
One might also argue....

Yoga Time

Music Instruction

Collaborative play

Pretend play/imitation
Outstanding Questions and Future Directions

• It appears we know we can improve EF but not how much or for how long or what this does in other domains
• Diagnosis/population specific, or tailor to phenotypes?
• How can we make this more accessible?
  • Study of other ‘readily available’ activities
  • Training community resources, integrating principles of interventions in schools and other activities
• Are we improving or normalizing?
• Can we demonstrate a meaningful impact on other outcomes (e.g., transfer)
• What factors influence maintenance of gains
• Impact of motivation
Thank you for your attention!
Educational Options in School Districts: What Parents Need to Know

Wanda Rankin
Education Specialist
CANDO Program
Every Student Succeeds Act (ESSA)

❤ No Child Left Behind (2002-2015)
❤ Law signed on December 10, 2015
❤ Longstanding commitment to equal opportunity for all students
❤ High academic standards to prepare students to succeed in college or career
Section 504

❤ Rehabilitation Act of 1973
❤ Civil rights law which protects the rights of individuals with disabilities in programs and activities that receive federal financial assistance
❤ A student who has a disability which substantially limits one or more major life activities
  • Major life activities can include: eating, breathing, walking, learning, concentrating, thinking, or caring for oneself
❤ Accommodation plan developed
Individuals with Disabilities Education Act (IDEA) 2004

♥ Covers students from birth through high school or age 21

♥ Schools cannot deny an education to students with disabilities.

♥ Schools must evaluate the extent to which students receive appropriate learning experiences.

♥ Schools must monitor students’ responses to research-based interventions; specifically in regard to identifying specific learning disabilities.
Early Intervention/Infant and Toddler Program/Child Find

❤️ Provides early intervention, special education and related services for children birth through five (prior to kindergarten)

❤️ Services focus on helping families learn ways to help their child learn and grow with everyday activities.

❤️ Includes evaluation and an individually designed plan of instruction for young children with special needs
Promoting School Success

❤ Child Find
  • School Age Students (Private School, Parochial School, Home School)

❤ School districts use a multi-tiered approach
  • Early identification
  • Support students with learning and behavior needs

❤ Struggling learners are provided with interventions at increasing levels of intensity to accelerate their rate of learning.
Some school districts use the Response to Intervention (RtI) model.

Response to Intervention (RtI) is a research based process developed to help struggling students at the earliest signs of need (academic and behavior) while in the general education classroom.
Response to Intervention (RtI)

- **Tier 1**: Core Classroom Instruction for All. Intervention for all students by differentiating instruction. (80%)
- **Tier 2**: Targeted Small Group Interventions. Strategic Interventions for student “at risk” of failure; supplemental support with increased time and intensity. (15%)
- **Tier 3**: Intensive, Individualized Interventions. Customized support for “at-high-risk” students (one-to-one or small group). (5%)
- **Tier 4**: Special Education. What happens after SPED recommendation or a service delivery model integrated within tier of instruction matched to the student's skill needs.

Special Education Eligibility & Determination
Benefits of Response to Intervention (RtI)

- Focus on data to better address students’ needs
- Eliminate “Wait to Fail” model
- Reduces drop-out rates
- Transition from remedial to acceleration or even AP classes
- Increase graduation rate
- Reduction in number of suspensions
- Decrease in behavioral referrals
Response to Intervention (RtI)

❤️ At any point in the RtI process, IDEA 2004 allows parents to request a formal evaluation to determine eligibility for:
  • 504 Plan
  • Special Education Services

❤️ The RtI process cannot be used to deny or delay a formal evaluation for special education services.
Parent Involvement

❤ You have a say in the decisions the school makes about your child’s education.
❤ Only you have an in-depth, long-term, daily relationship with your child.
❤ You are the only permanent member of the school-based team.
❤ When parents are involved, children do better and schools become better.
How Can Parents Participate Effectively?

- Understand your rights
- Prepare for and attend meetings
- Read your child’s school records
- Understand and ask questions
- Put things in writing
- Recognize different roles you and school staff play
I offer support to you and your child while your family is in our care. This includes:

- Discussing the educational options in your school district to support your child, like **Home and Hospital Instruction (HHI)**, **504 Plans**, **Individualized Education Programs (IEPs)**
- Connecting you with resources needed to make informed educational decisions
- Helping you resolve concerns
- Providing information to increase awareness of community services
Resources for Families

❤️ Children’s National Medical Center Home Page

• Cardiac Neurodevelopmental Outcome Program (CANDO) Site
  ▪ Home and Hospital Instruction
  ▪ Navigating the 504 and Special Education Processes
  ▪ When your Child Has Problems in School
  ▪ Neuropsychological Testing Versus Educational Testing
  ▪ Educational Websites
  ▪ Advocacy Resources
CANDO Program Overview

• Cardiac Neurodevelopmental Outcomes
• Goal: identify and manage any developmental problems through routine screening and surveillance

• Melissa Duva, Program Coordinator
Who are our CANDO patients?

• Had heart surgery in the first year of life
• Has a cyanotic heart defect (a congenital heart defect that results in a "blue" baby with lower than normal blood oxygen level)
• Has a heart defect and neurologic risk factor such as stroke, seizure or other neurological abnormality – even if surgery was not required
• There is a developmental concern during a routine exam in a child with CHD, even if surgery was not required
CANDO Inpatient

CANDO PROGRAM ROAD MAP

- Developmental Rounds
- Child Development Evaluation
- Neurology Evaluation
## CANDO Outpatient

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<th>CHILD DEVELOPMENT EVALUATION</th>
<th>NEUROLOGY EVALUATION</th>
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<td>6-9 month old visit</td>
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Multidisciplinary Clinic

- Started October 2017
- Nutrition, Speech, Child Development and Neurology
- Reduces number of overall visits
- Multidisciplinary collaboration and patient education
- Currently age 3 and under
How do I get in touch with CANDO?

- Call me! 202-476-6867
- Email me! Mduva@childrensnational.org
- Kids at any age can enter the program
Advice for Parents

• Talk to your Cardiologist about Neurodevelopment
• Talk to our team about programs in your local area- we can help you get connected
Nationwide Collaboration

• CNMC Team activity in CNOC
  • Jacquie Sanz – First elected Co-Chair
  • Gil Wernovsky – Chair of the Program and Meetings Committee
  • Mary Donofrio - Member of the Program and Meetings Committee
  • Melissa Duva- Member of the Quality Improvement Committee

• Children’s National – Home of the Neurodevelopmental Core Lab, PI Jacquie Sanz
Institutional Members
Our Team
Contact Information

- Dr. Mary Donofrio- Program Director
- Dr. Jacqueline Sanz- Program Director
- Melissa Duva- Nurse Coordinator
  - Mduva@childrensnational.org
- Wanda Rankin- Educational Specialist
  - wrankin@childrensnational.org
Maximize Your Child’s Potential for a Bright Future

The Cardiac Neurodevelopmental Outcome (CANDO) Program is the region’s only program designed specifically to monitor neurodevelopmental growth in children born with congenital heart disease.