Neurodevelopmental Follow Up in Children with Congenital Heart Disease

The CANDO Program at Children's National

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Neuropsychologist

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Overview

- Neurodevelopmental Signatures in CHD
- Review of AHA Guidelines for follow up (Marino et al., 2012)
- Cardiac Neurodevelopmental Outcome (CANDO) Program
- Suggestions for partnership with primary care

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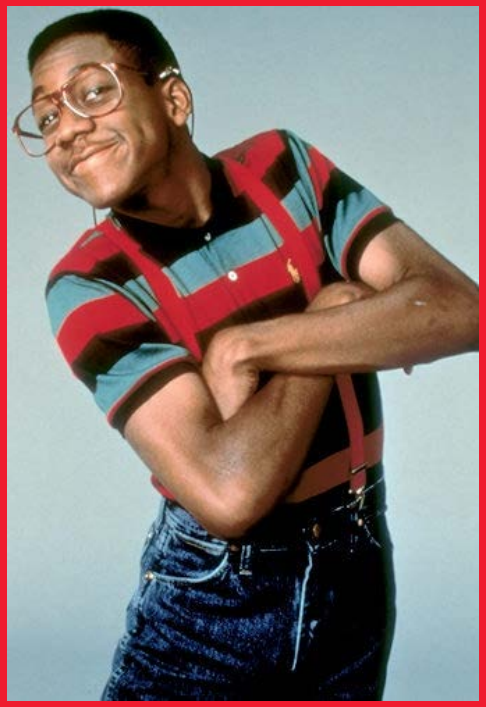
Neurodevelopmental Signatures in CHD across the lifespan



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Infancy – Neuroanatomical Differences

- Neurological abnormalities are present before any intervention, even in utero.
  - Fetal MRI in 3rd Trimester (Limperopoulos et al., 2010):
    - Smaller total brain volumes
    - Lower NAA:Choline Ratios
  - Infants (Wanatabe et al., 2009):
    - Reduced global gray matter volumes (especially frontal lobe)
    - Higher incidence of white matter injury
    - This relates to hypoxia and to motor development

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Infancy through Preschool – Developmental Abnormalities

- Infancy:
  - gross motor development most affected
  - 44% of children with CHD have at lest one area of delay (cognitive, speech, motor)
  - Of those that meet criteria for early intervention, only 31% are enrolled in early intervention services.
- By Preschool:
  - IQ scores are “normal” but problems with:
    - Oromotor/facial movement/speech/language
    - Motor delays
    - Visual-motor skills

Brosig et al 2011; Bellinger et al 1995

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School Age

- Most have “normal” IQ
- Neurodevelopmental ‘signature’ with problems in:
  - Attention/Executive Skills
  - Visual-spatial skills
  - Fine motor/visual motor skills
  - Higher order language/social skills
- Over 1/3 receiving academic/school services
- 1/5 reporting behavioral concerns
- Few differences based on type of surgical intervention(bypass vs. arrest)

Bellinger et al., 2003, 2009

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Adolescence and Adulthood

- 65% receiving school/academic services
- 33% have MRI abnormalities (vs. 4% in control population)
- Neurodevelopmental ‘signature’ evolves with problems in:
  - Attention/Executive skills, memory, visual spatial skills, social cognition.
- Adulthood: less research but concerns with
  - Transition to adult care
  - High prevalence of psychiatric disorders

Bellinger et al., 2011

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Review of AHA/AAP Guidelines for Neurodevelopmental Follow Up in CHD

Marino BS, Lipkin PH, Newburger JW, Peacock G, Gerdes M, Gaynor JW, Mussatto KA, Uzark K, Goldberg CS, Johnson WH Jr, Li J, Smith SE, Bellinger DC, Mahle WT, 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. Neurodevelopmental outcomes in children with congenital heart disease: evaluation and management: a scientific statement from the American Heart Association. *Circulation*. 2012; 126.

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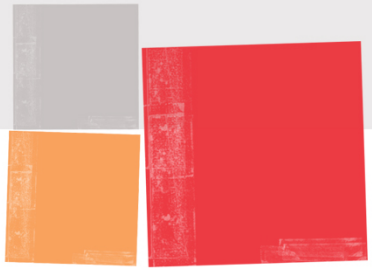
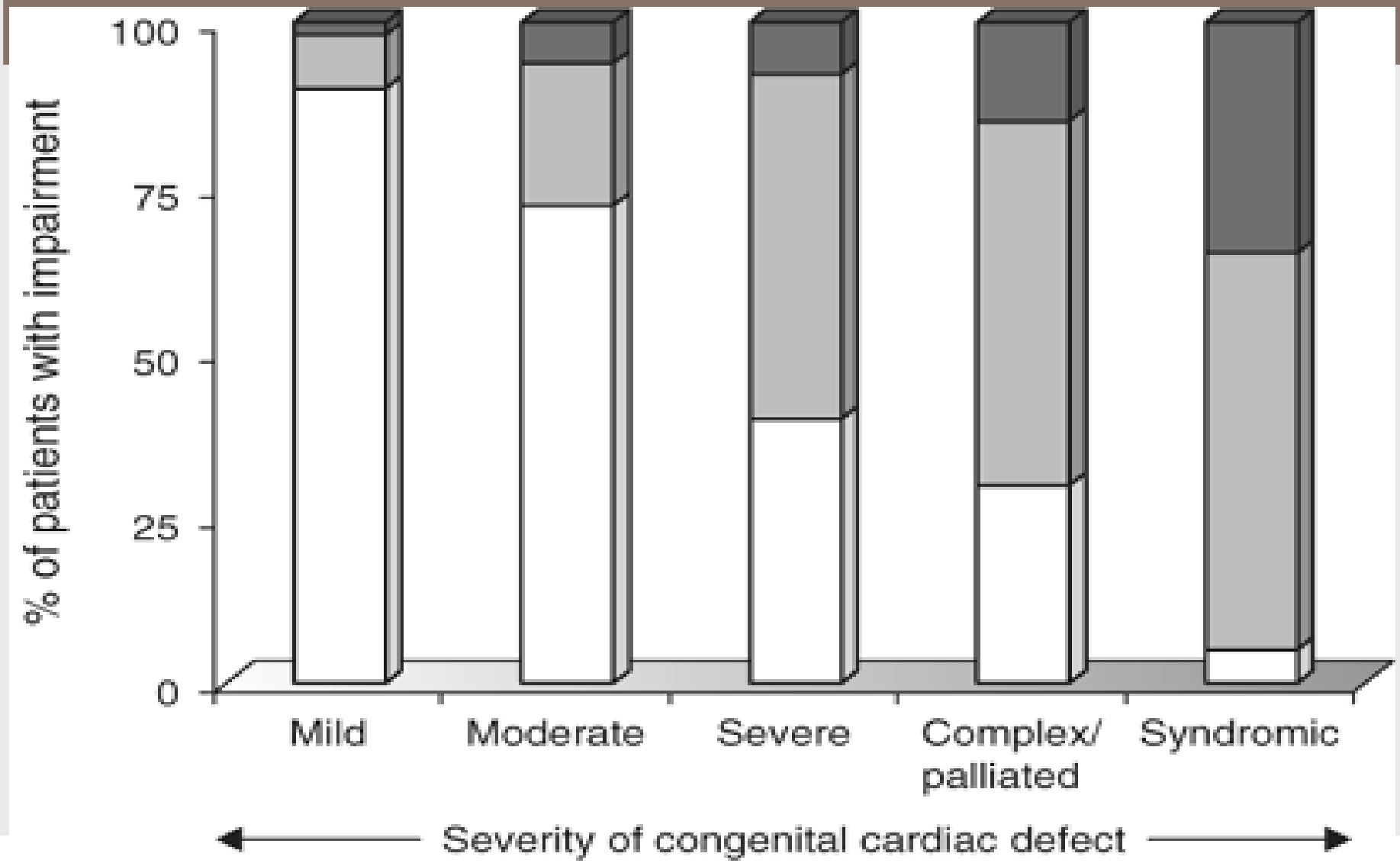
Terminology

- Surveillance
  - “the process of recognizing children who may be at risk for developmental delay”
- Screening
  - “the use of standardized tools to identify and refine the risk recognized from surveillance”
- Evaluation
  - “a complex process aimed at identifying specific developmental disorders or disabilities that are affecting a child”



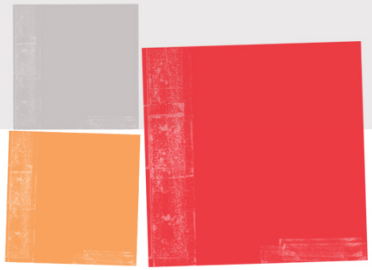
Risk Categories and level of follow-up



Wernovsky, 2006

HIGH Risk Category

- **Any patient with CHD that has open heart surgery < 1 year of age**
- **Any patient with cyanotic CHD**
- **Any patient with CHD and one or more risk factors:**
  - Genetic syndrome (suspected or diagnosed)
  - Prematurity (< 37 weeks)
  - Developmental delay in infancy
  - Mechanical support (ECMO and/or VAD)
  - Heart transplantation
  - CPR at any point
  - Prolonged hospitalization (>2 week LOS in the hospital)
  - Perioperative seizures
  - Neuroimaging abnormalities
  - microcephaly



SURVEILLANCE

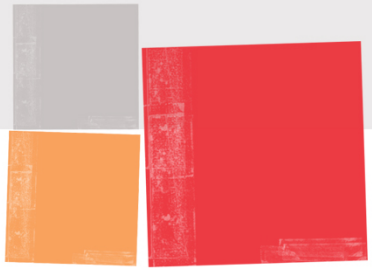
- In ALL children with congenital heart disease

SCREENING

- When a concern is identified through surveillance for ALL children with CHD.
- Per previous AAP guidelines.

EVALUATION

- For ALL HIGH RISK CHD
- When concerns identified with screening and/or surveillance
- In any child with CHD if the medical home provider deems necessary or appropriate



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CANDO Program

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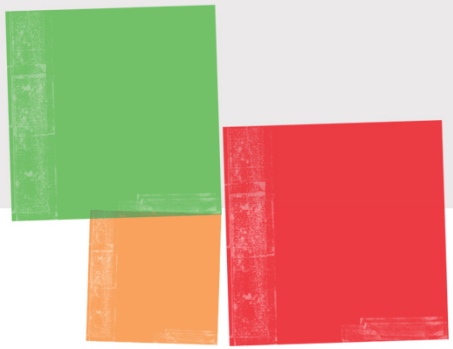
CANDO Program

- Evaluation schedule that follows AHA guidelines
- Identifies any problems
- Provides recommendations for treatment planning
- Communicates findings back to medical home and cardiology
- Monitors progress and treatment effectiveness in a standardized way



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Our Team

Jacqueline Sanz, PhD
Co-Director and Neuropsychologist

Mary Donofrio, MD
Co-Director and Cardiologist

Penny Glass, PhD
Developmental Psychologist

Judy Brown, NNP
Neonatal Nurse Practitioner

Jessica Carpenter, MD
Neurologist

Thanh Nguyen, MD
Neurologist

Appointments

For more information on the clinic, and to schedule an appointment, call our Program Coordinator at 202-476-6867.

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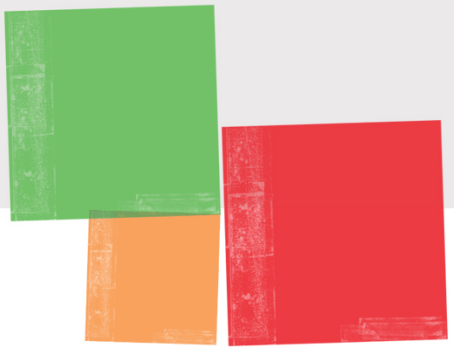
Infants and Toddlers (ages 0-3+)

- Inpatient consultation at time of surgery:
  - Developmental specialist, Neurology
- Initial outpatient appointment at 6 months of age (developmental and neurology)
- Developmental evaluations:
  - 9 months
  - 12-24 months
  - 30-36 months



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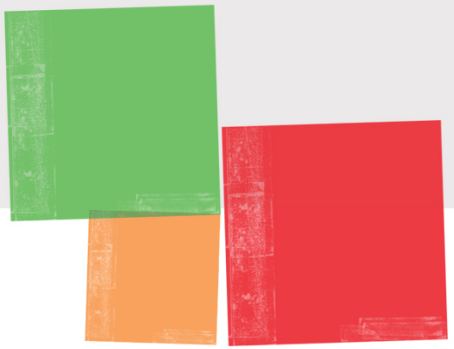
School age through Teenage (4+)

- 4-5 years: School readiness visit (neuropsychology and neurology)
- 11-12 years: Middle school visit (neuropsychology)
- Additional evaluations at the discretion of the providers/medical home



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Partnering with primary care – the pediatrician's role

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SURVEILLANCE

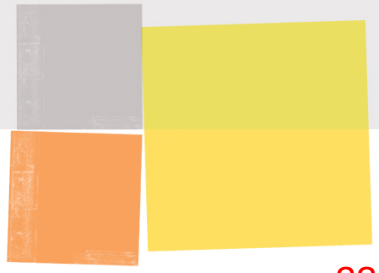
- Developmental surveillance at all well child visits.
- For children with CHD this includes attending to:
  - RISK stratification
    - Are one of the risk factors present? Does the child need formal follow up?
  - Asking the right questions
    - Consider using screening tools to help
  - Documentation of milestones, observations

SCREENING and REFERRAL

- Per AAP recommendations:
  - At 9, 18, 30, 48 months
  - Autism screening at 18 and 24 months
  - Continue to watch for “ADHD” and other behavioral/emotional problems
- Use AAP recommended tools, for example:
  - Ages and Stages, Brief Infant Toddler Social Emotional Assessment, Pediatric Symptom Checklist, Vanderbilt (for ADHD), CHAT (for Autism)
  - For Autism, see Johnson CP, Myers SM *Pediatrics*, 2007, 120: 1183-1215
- REFERRAL to neurodevelopmental clinic for further evaluation if a problem is suspected.

COMMUNICATION and Partnership

- “Medical home”
- Regular communication with specialists to help implement the therapeutic recommendations.
- Facilitating referrals for early interventions and other therapeutic programs



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Acknowledgements

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Jessica Carpenter, M.D. (Neurologist)
Thanh Nguyen, M.D. (Neurologist)

Research Team:
Chelsea Sharber, M.A.
Kami Todd, R.N.

Please visit the Neuropsychology table at the exhibition for more information and brochures

CONTACT INFORMATION: jsanz@cnmc.org; 202-476-6867

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