

FROM FETUS TO FIVE:

THE STRESS RESPONSE IN MEDICALLY COMPLEX CHILDREN

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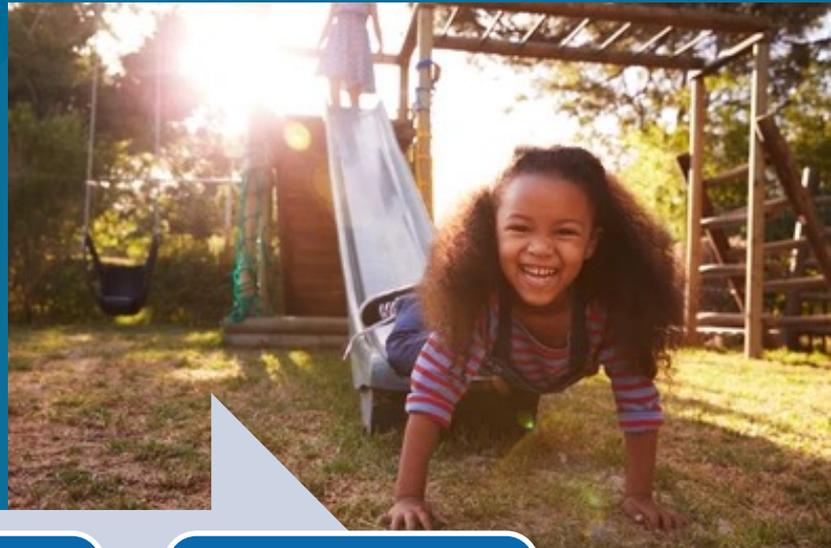


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Objectives

- To understand the effects of prenatal stress and perinatal experiences on attachment, early development, and behaviors in medically complex children.
- To appreciate the impact of the parents' experience from the time of diagnosis on parent-child bonding and the child's development and behaviors.
- To identify resources for early identification and support of behavioral and developmental challenges.

Outline



Perinatal-
Infancy

1-3 years

3-5 years



THE STRESS RESPONSE

Biology of the Stress Response



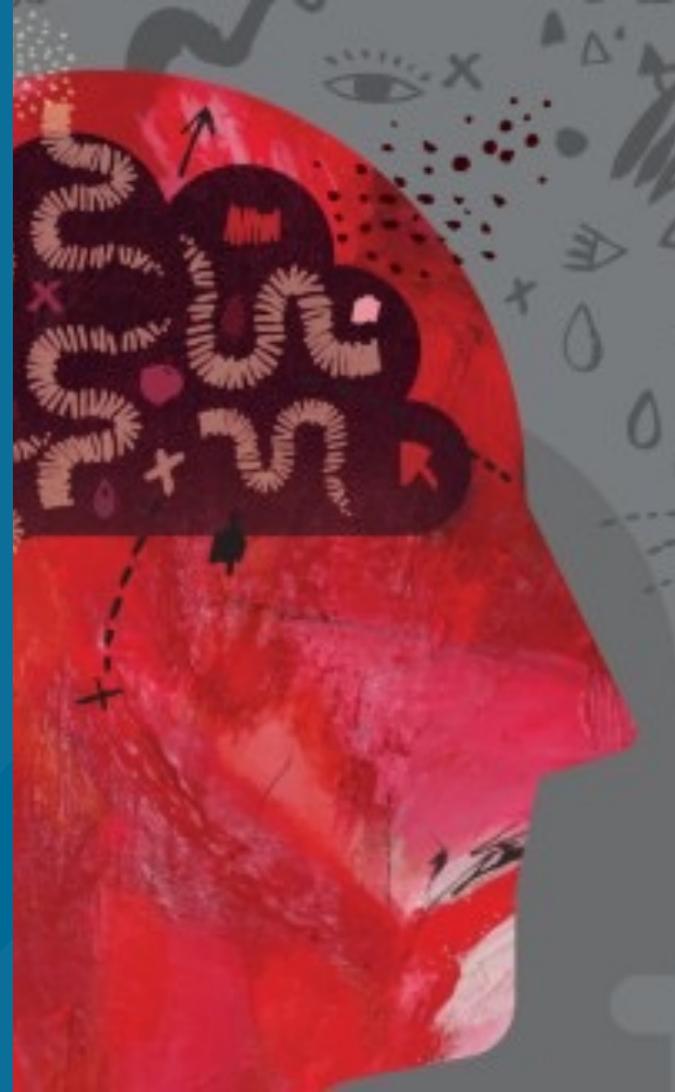
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Definitions

- **Children with medical complexity (CMC)** have multiple significant chronic health problems that affect multiple organ systems and result in functional limitations, high health care need or utilization, and often the need for or use of medical technology.
- **Children and youth with special health care needs (CYSHCN)** require health and related services for a chronic physical, developmental, behavioral, or emotional condition beyond what is typically required for children.

Definitions

- **Physiological Stress**- a threat to well-being that causes activation of neurobiological systems to preserve or restore homeostasis necessary for survival
 - Ex. Response to cold or starvation
- **Psychosocial Stress**- the consequence of an imbalance between adverse experiences in our everyday lives and our ability to cope with them.
 - Ex. Divorce, prolonged illness



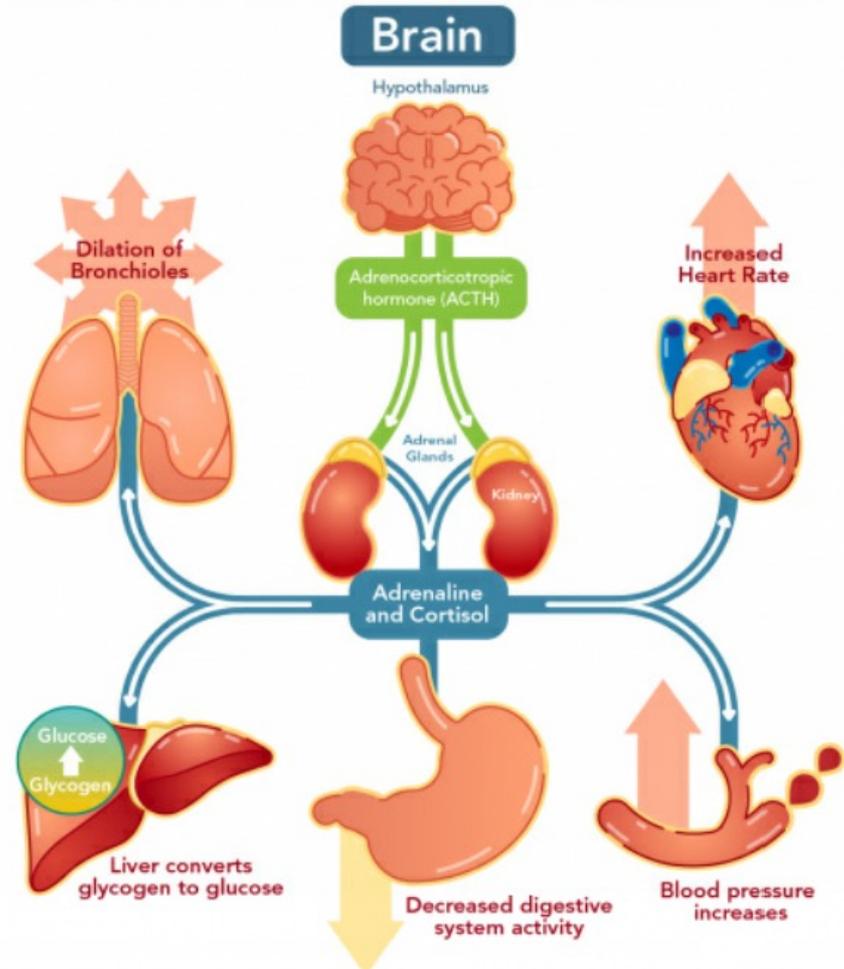
Stressors

- Begin prenatally and continue through critical periods of development
 - Parental stressors related to diagnoses
 - Repeat or prolonged hospitalizations
 - Medical procedures/surgeries
 - Frequent appointments
- **Medical traumatic stress** refers to a set of psychological and physiological responses of children and their families to pain, injury, serious illness, medical procedures, and invasive or frightening treatment experiences. Medical trauma may occur as a response to a single or multiple medical events.

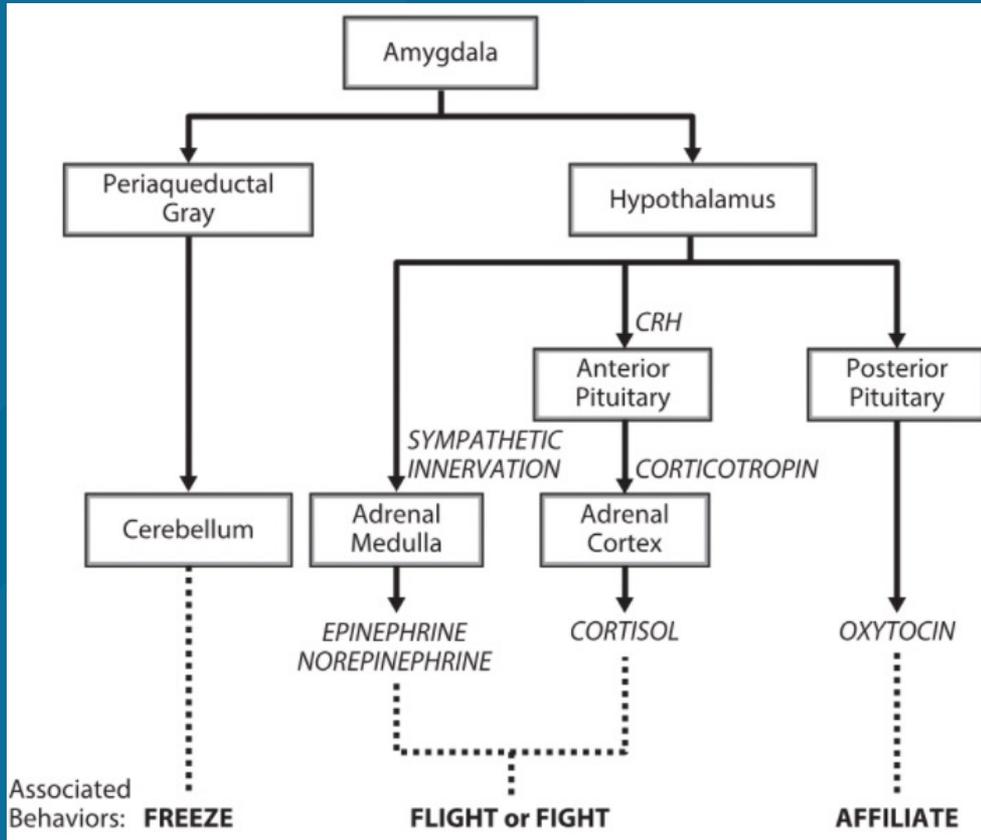
Biology of the stress response

- HPA axis
- Stressful situations perceived
- Hypothalamus starts the body's response
- Pituitary gland receives a message from the hypothalamus and forwards it to the adrenal glands
- Adrenal glands release cortisol into the blood stream along with epinephrine and norepinephrine
- Cortisol helps the liver release glucose to prepare for "fight or flight". Epi & Norepi increase our heart rate and breathing which use the excess glucose

STRESS RESPONSE SYSTEM



The Stress Response



Effects of Chronic Stress

- Overstimulation of the HPA axis → overdevelopment of the limbic system
 - Larger amygdala
 - Atrophy of the hippocampus
 - Prefrontal cortex altered connectivity/functioning

Prefrontal Cortex

Regulates thoughts, emotions, behavior

Hippocampus

Stores learning and memory

Amygdala

Reacts to stress and emotional arousal

Prefrontal Cortex

Structural changes including fewer and altered connections
Functional challenges including difficulty regulating thoughts, emotions, behavior

Hippocampus

Structural changes including fewer connections, fewer new neurons created, and smaller volume
Functional changes including difficulty with memory, contextualizing new situations and information, and storing new learning

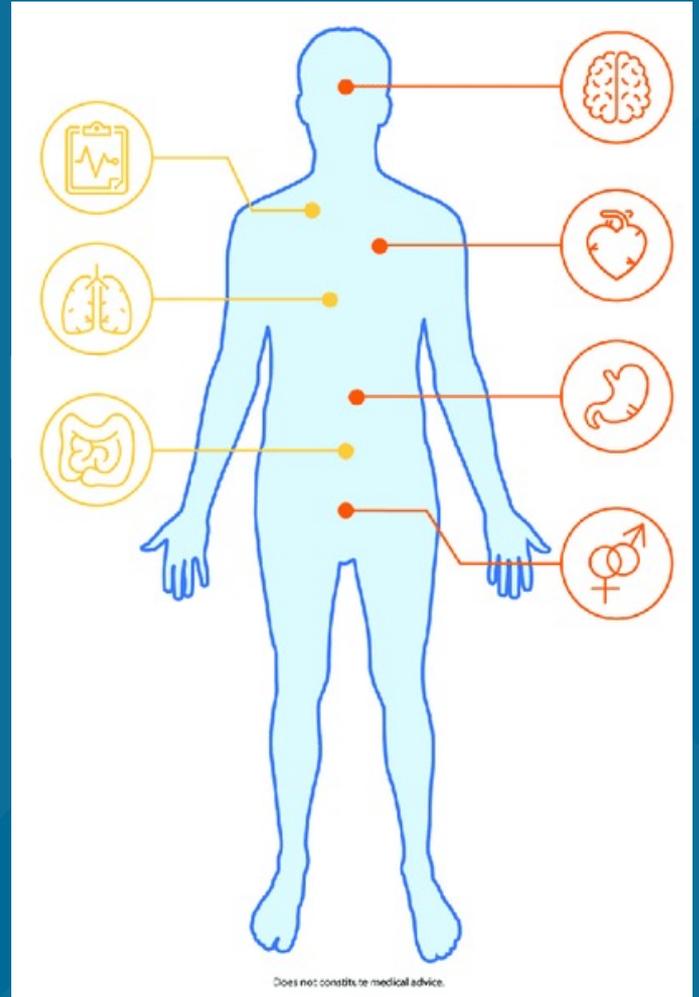
Amygdala

Structural changes including altered connections and volume
Functional changes including a hyperreactive stress response

**Stress Hormone
Cortisol**

Effects of Chronic Stress

- Immune dysregulation
- Metabolic effects
- Cardiovascular and respiratory effects
- Inhibited growth



Effects of Stress

- Child
 - Biologic and psychological effects
- Parent
 - Biologic and psychological effects
- Parent-child attachment and interaction



PERINATAL/INFANCY

Prenatal-1 year



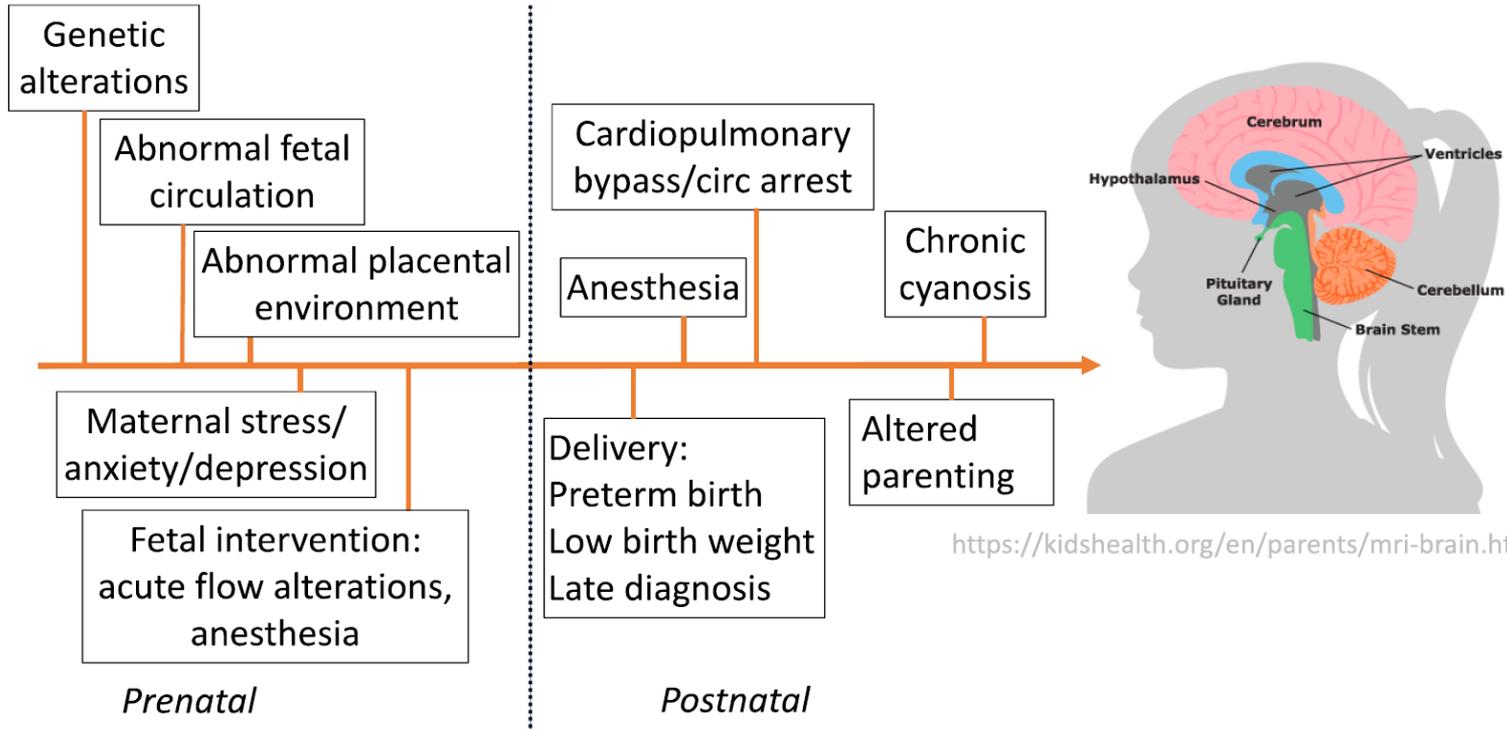
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Case Study

- John and Mary
 - 1st pregnancy
 - 20 weeks gestation
 - Fetal echo 2 weeks after hearing something was wrong with their baby's heart
 - Hear diagnosis of Hypoplastic Left Heart Syndrome for the first time
 - Planning for baby's arrival more muted
 - Unsure of baby's prognosis or survival
 - Mother very stressed, spends a lot of time crying
 - Father very stressed, spends time Googling diagnosis and keeping his emotions inside

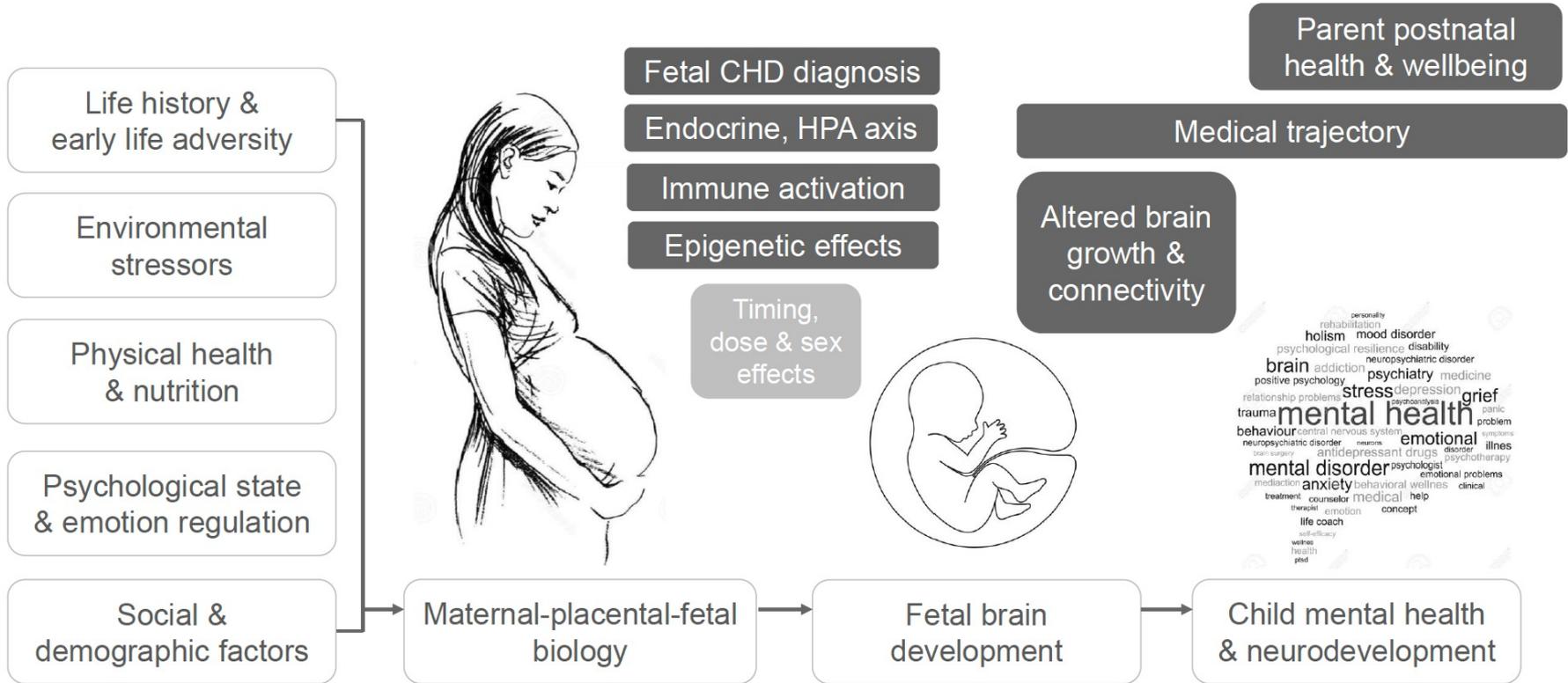


Potential Risk Factors for Neurologic Injury/Impairment in CHD

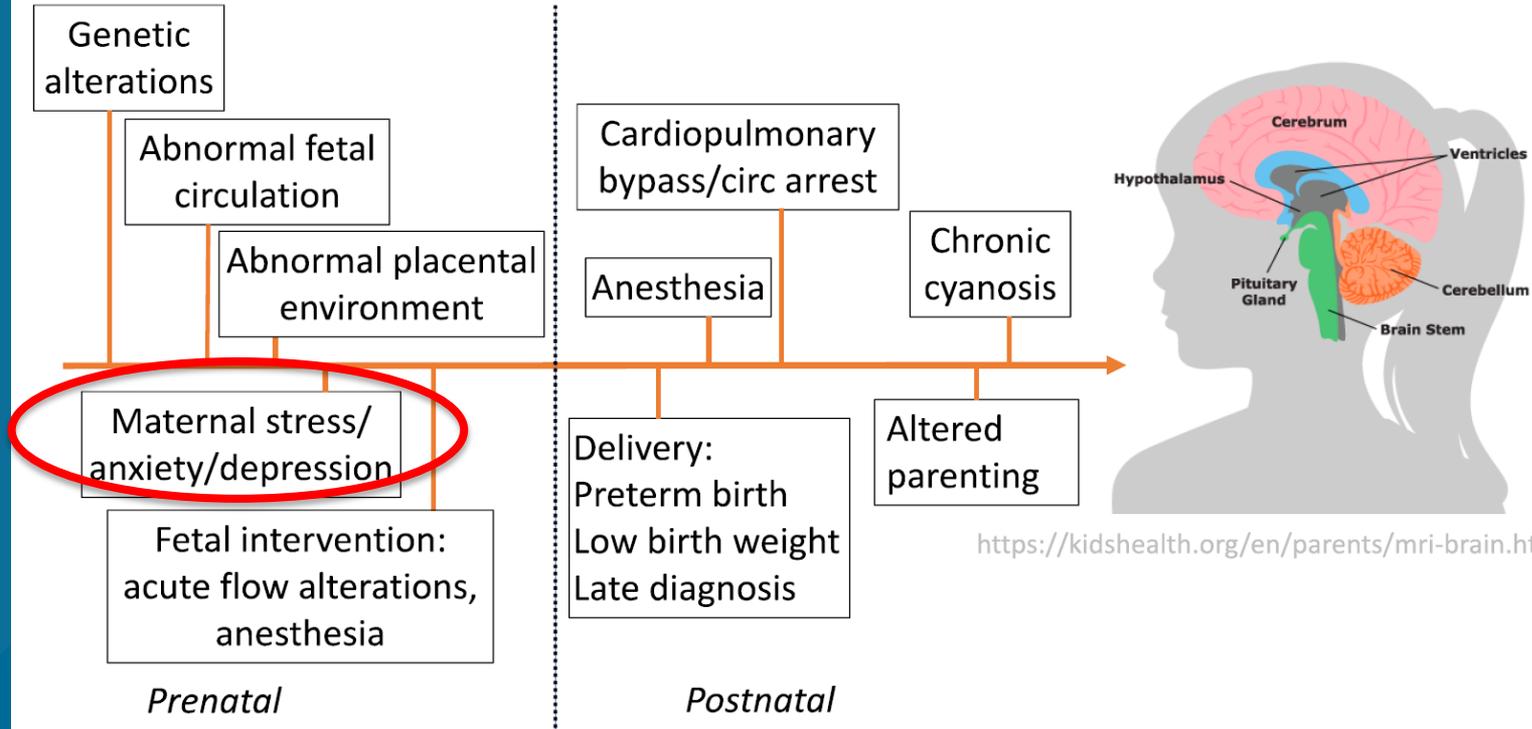


<https://kidshealth.org/en/parents/mri-brain.html>

Fetal origins of mental health



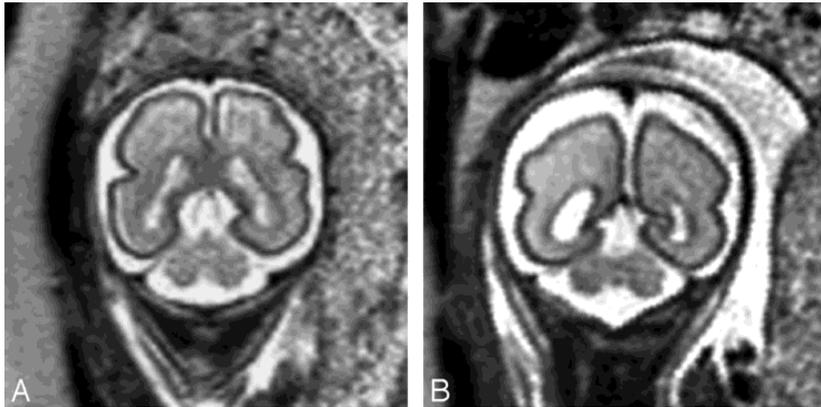
Potential Risk Factors for Neurologic Injury/Impairment in CHD



<https://kidshealth.org/en/parents/mri-brain.html>

Prenatal Brain Development

A, T2-weighted axial view of the brain of a healthy control at 26.56 weeks' GA. B, T2-weighted axial view of the brain of a patient with extra-axial spaces at 27.28 weeks' GA.

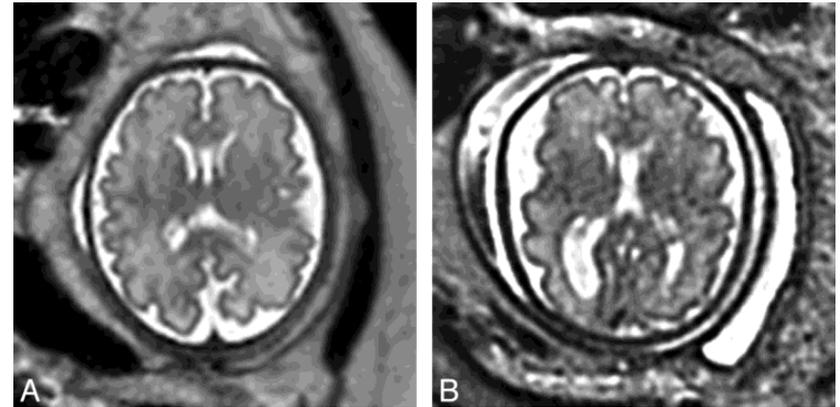


M. Brossard-Racine et al. AJNR Am J Neuroradiol
2014;35:1593-1599



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A, T2-weighted axial view of the brain of a healthy control at 32.55 weeks' GA. B, T2-weighted axial view of the brain of a patient with unilateral left ventriculomegaly at 32.00 weeks' GA.



M. Brossard-Racine et al. AJNR Am J Neuroradiol
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Case Study

- Jack is born



Case Study

- Jack is admitted to the CTICU



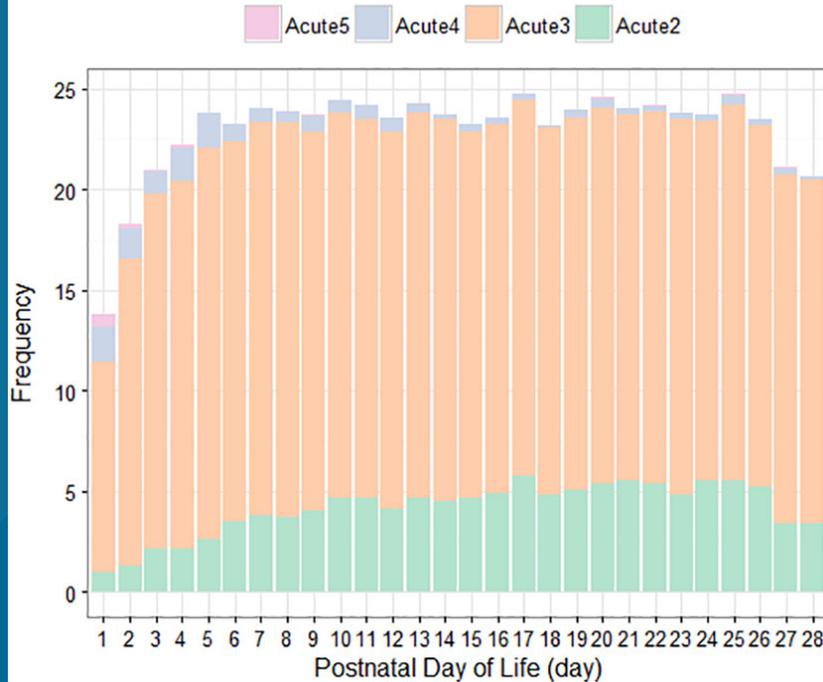
Case Study

- Cath Lab
- OR
- Cath Lab
- Chest closure

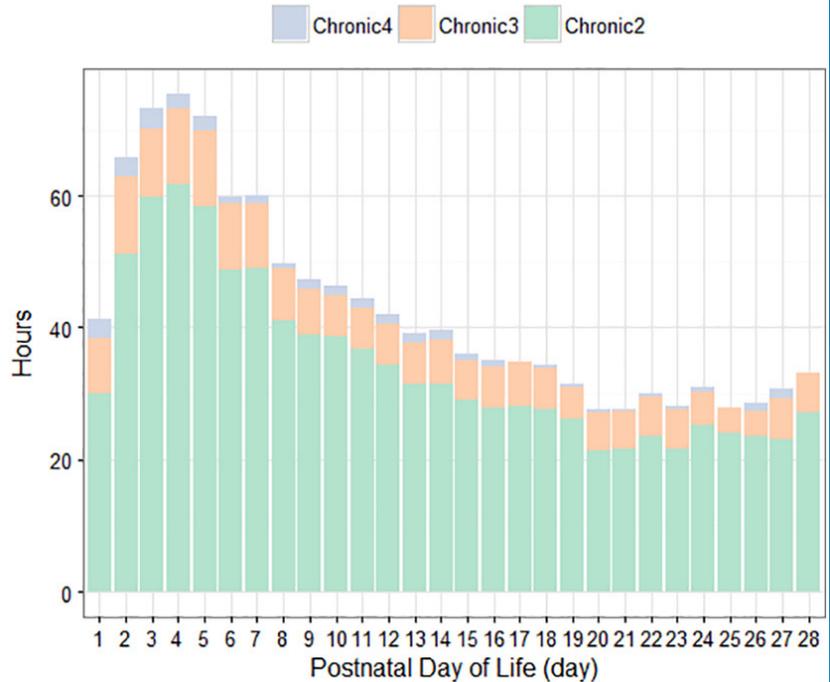


Acute and Chronic Stressors in NICU

A. Daily Acute Pain/Stressors



B. Daily Chronic Pain/Stressors



Parent Mental Health

- NICU Hospitalization
 - Up to 40% of mothers experience postpartum depression
 - 1/3 of parents report symptoms acute stress disorder
 - 10-20% progress to PTSD symptoms
 - Stressors: Health of infant, Life threatening experiences, Parent-infant separation

Case Study

- Feeding issues



Protective factors

- Assessing parent mental health in NICU
- Skin to skin data
- Single family rooms
- Breastfeeding

Case Study

- Feeding issues



Case Study

Jack is 6 months old

BDG/Stage II



Case Study

Jack is 12 months

HRI visit



Attachment/Attunement

- **Attachment**-the emotional bond between parents and children
- **Attunement**- how reactive a person is to another's emotions/needs

Impacts of COVID

- Limited visitation
- Mask wearing
- Access to in person services
- Additional parental stress



Resources

- First 5 First Steps
- California Early Start/SDRC
- Zero to Three, zerotothree.org
- HealthyChildren.org



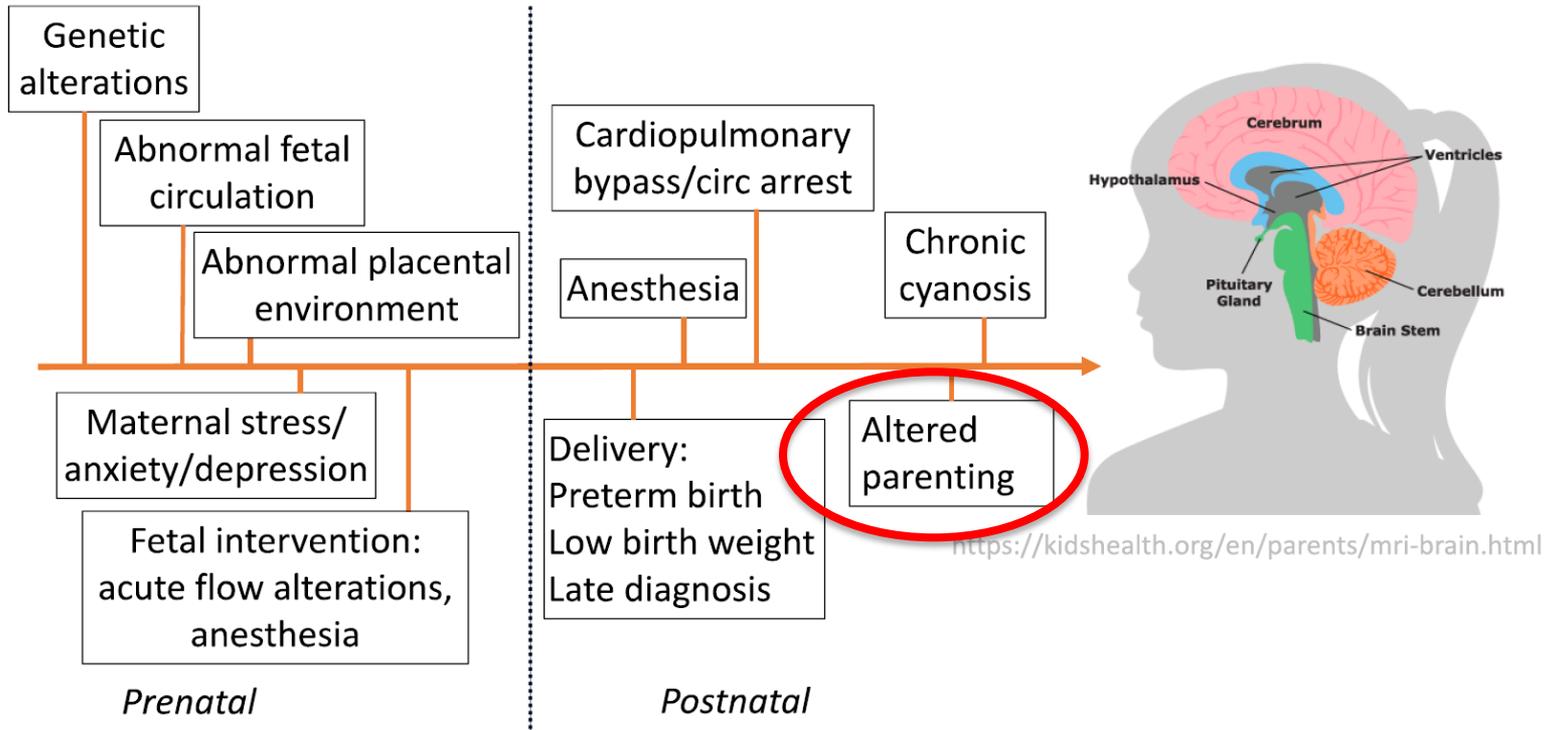
TODDLER YEARS

1-3 years



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Potential Risk Factors for Neurologic Injury/Impairment in CHD



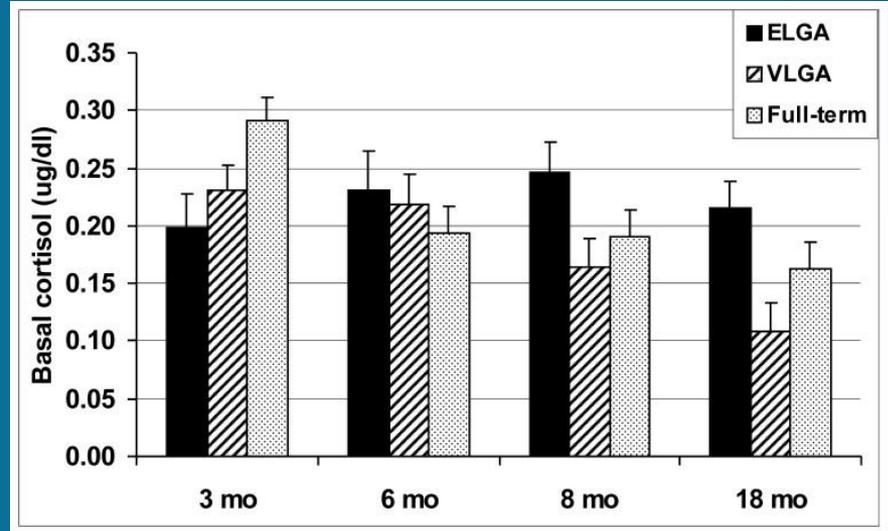
Case Part 2

- 2 years – HRI
- 2.5 Pre-Fontan Cath



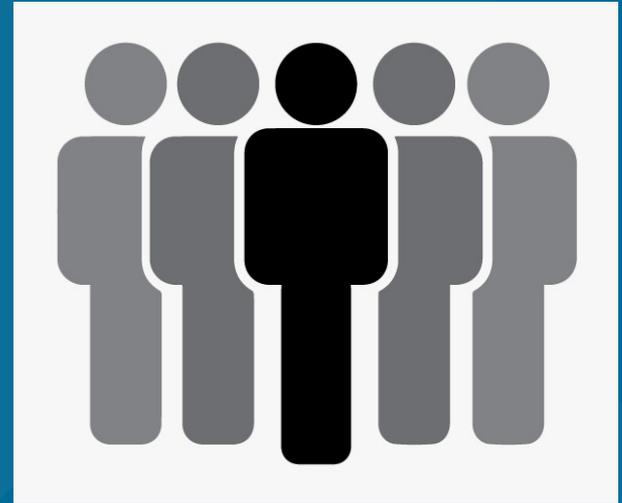
Biology

- Altered HPA axis functioning is noted shortly after birth and dynamically changes in first few years of life in Infants and toddlers born preterm
 - At 3 months, lower basal cortisol levels
 - At 8 and 18 months, increased basal cortisol levels
- Overall elevation of the cortisol “set point” in response
- Study of 18-month-old toddlers showed abnormal response to bumps and bruises
 - Parents rated lower pain sensitivity



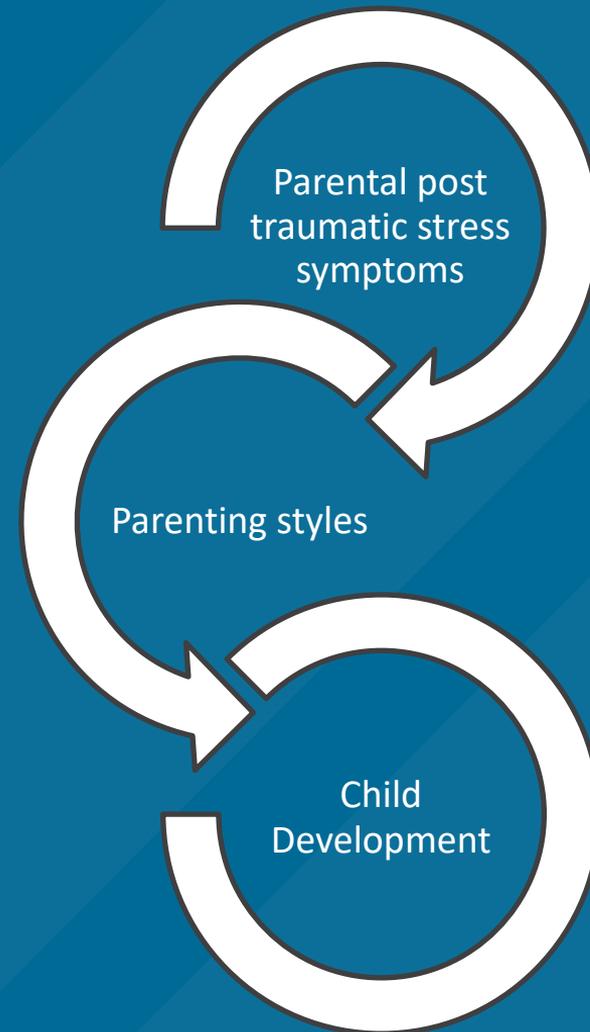
Parent Stress

- Posttraumatic stress symptoms in parents of very preterm infants
 - 1/3 of parents at term equivalent age
 - ~25% of parents at 12 months of age
 - ~20% of parents at 2 years of age



Effects of Stress on Parenting

- Less effective in structuring infant interactions
- More controlling and less sensitive parenting
- Risk of insecure attachment



Resources

- First 5 – Healthy Development Services
- California Early Start/SDRC
- Rady Developmental Evaluation Clinic (DEC)
- UCSD Developmental-Behavioral Pediatrics
- Rady KidSTART
- Web Resources:
 - AAP Healthy Children [healthychildren.org](https://www.healthychildren.org)
 - Zero to Three, [zerotothree.org](https://www.zerotothree.org)
 - Child Mind Institute <https://childmind.org/>



PRESCHOOL YEARS

3-5 years



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Case Part 3

- Medical follow up appointments
- School transition



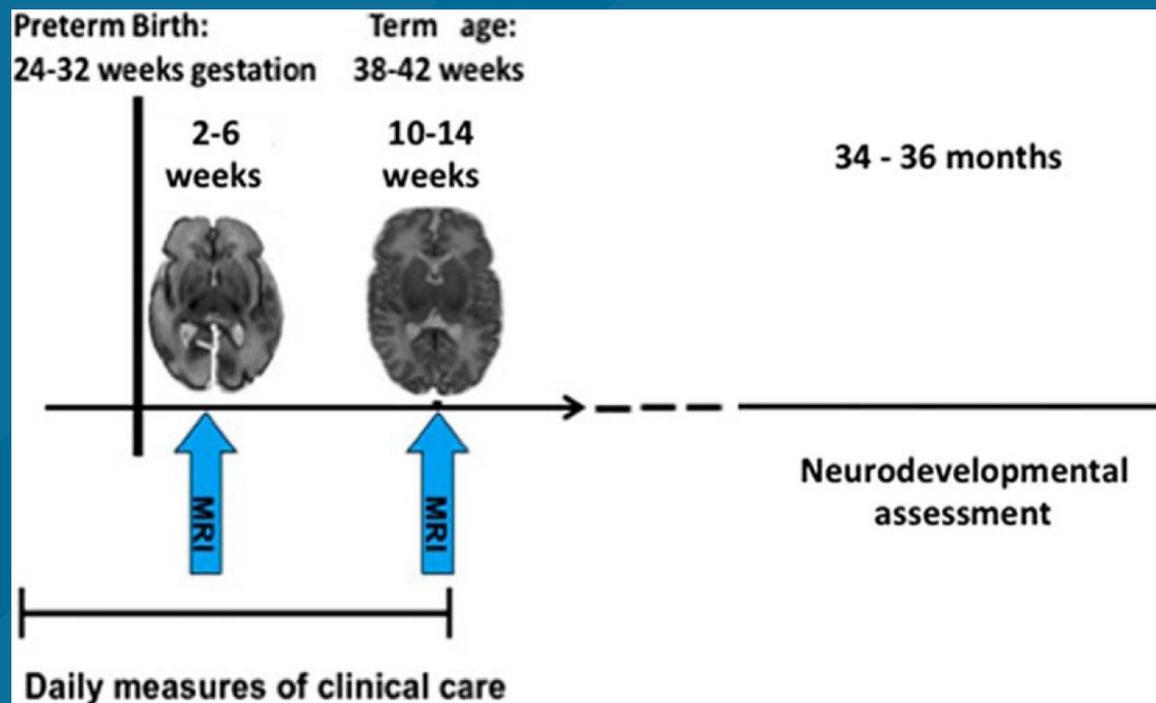
Biology

- In early childhood, activity of the HPA axis is shaped by environmental and relational influences
- Altered cortisol patterns persist into later in childhood
 - Children who have undergone cardiac surgery (<6 months of age) show altered HPA axis regulation at 3-5 years of age
 - Children born preterm continue to have differences in cortisol patterns at age 7
- Dysregulation of the HPA axis → poorer neurocognitive and psychological outcomes

Early pain associated with altered neurodevelopment

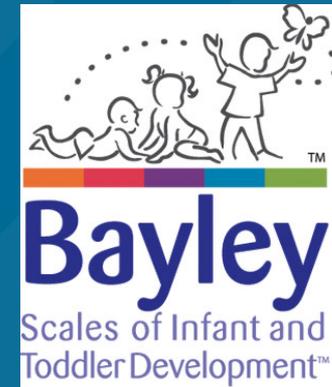
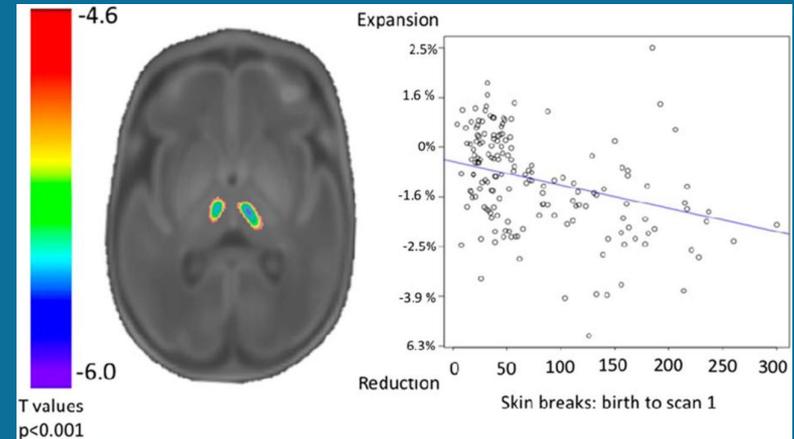
- Altered thalamic growth
- Smaller cerebellar volume
- These changes are associated with neurodevelopmental differences

Early pain associated with altered neurodevelopment



Early pain associated with altered neurodevelopment

- Early painful procedures were associated with slower thalamic growth
- Thalamic growth mediated neurodevelopmental outcomes
- Cognitive and motor scores at 3 years were lower in those with slower thalamic growth

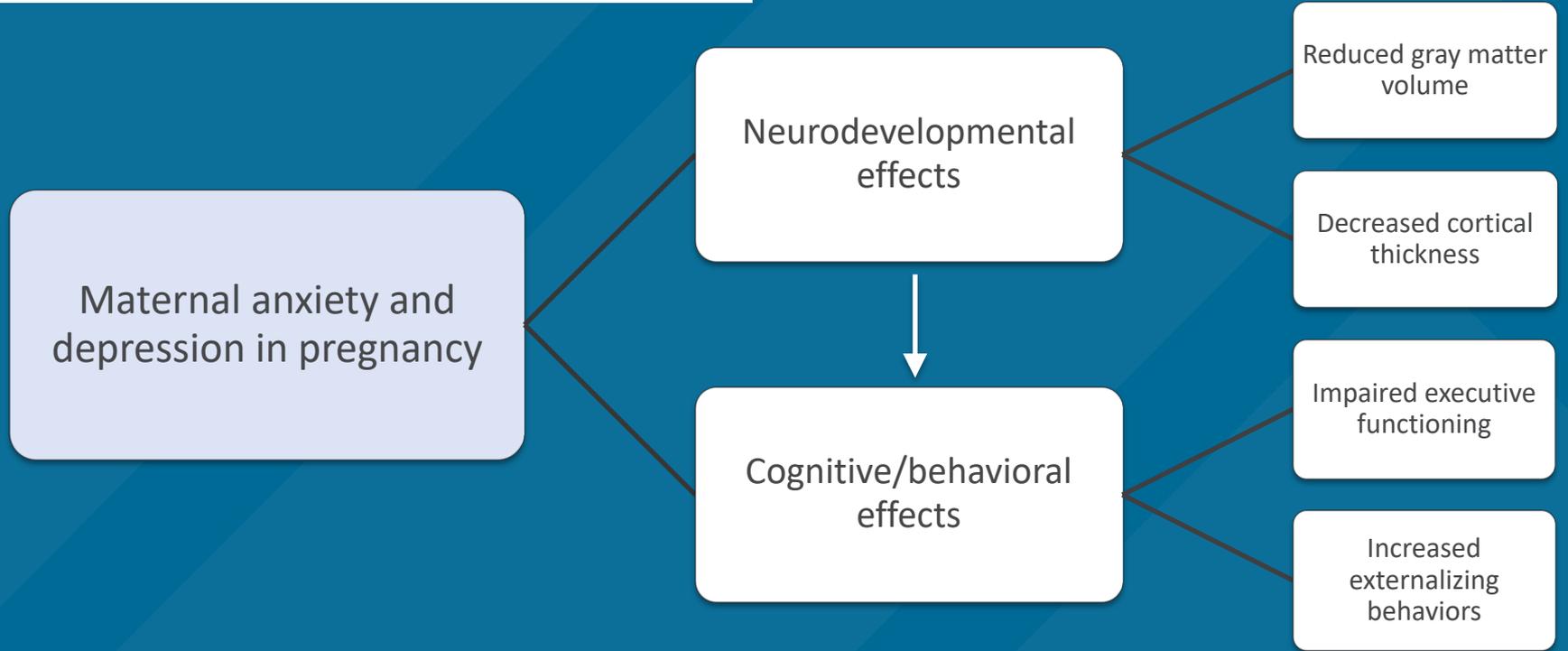


Parental Stress

- Effects of early stress
- Ongoing stressors

Parental Stress

Child Outcomes at 6-9 years



Parental Stress

- Early parental stress has long term significance in child development
- Study of prematurity, maternal stress, and IQ
 - Very preterm children vs term controls
 - Maternal PTSD symptoms rated at 18 months
 - IQ testing at 11 years
- Lower maternal PTSD scores at 18 months predicted higher IQ at 11 years of age

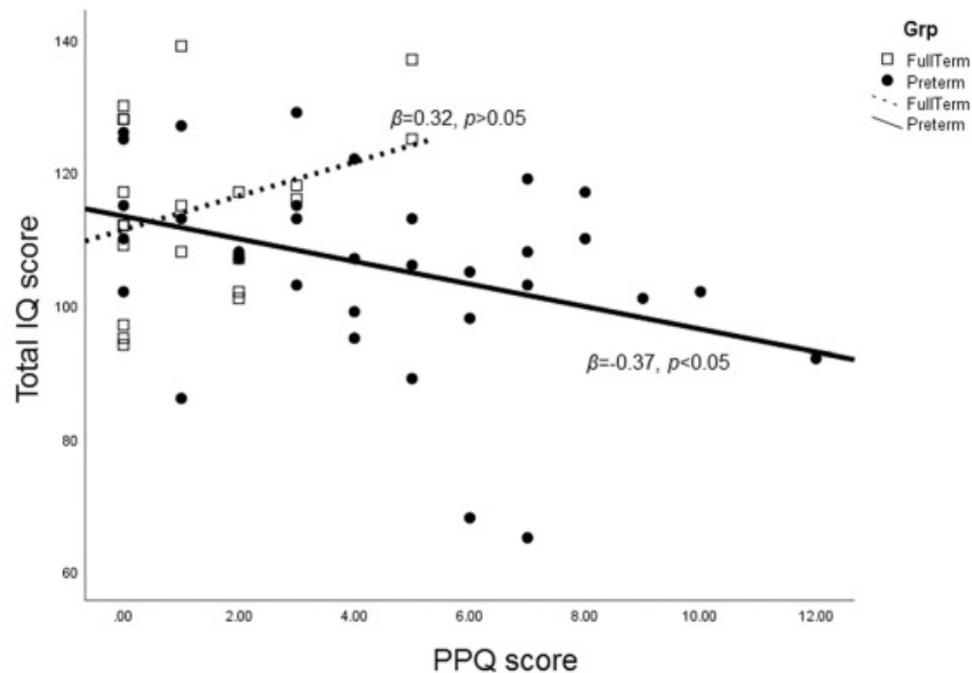


Figure 1. Effect of interaction between groups and PPQ on IQ score.

Parental Stress

- Rates of parental PTSD decrease over childhood
- Stress levels are associated with medical complexity and developmental difficulties and extend through childhood
- Study of 60k parent-child dyads
 - Parents of mental health, parents reported **poor or fair mental health:**
 - 18% of parents of CMC
 - 9% of parents of CSHCN
 - 3.5% of parents of non-CSHCN

Family Needs

Family challenges

- Care coordination
- Respite care
- Medical Equipment
- Multiple follow up visits

Cost

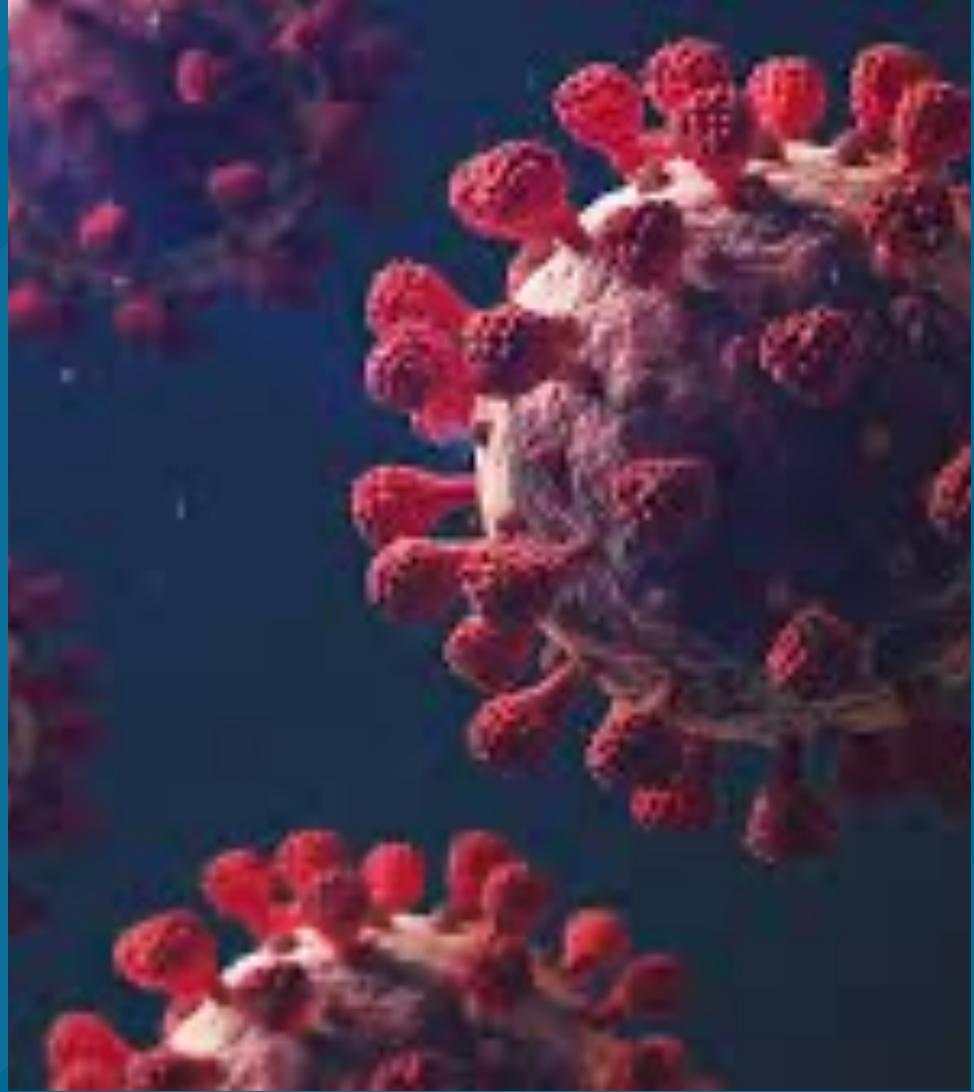
- Financial difficulties
- Employment loss
- Loss of relationships

Behavioral Impacts

- Impulsivity
- Attention problems
- Avoidance behaviors
- Sleep problems
- Aggressive play/outbursts
- Internalizing symptoms- anxiety, depression

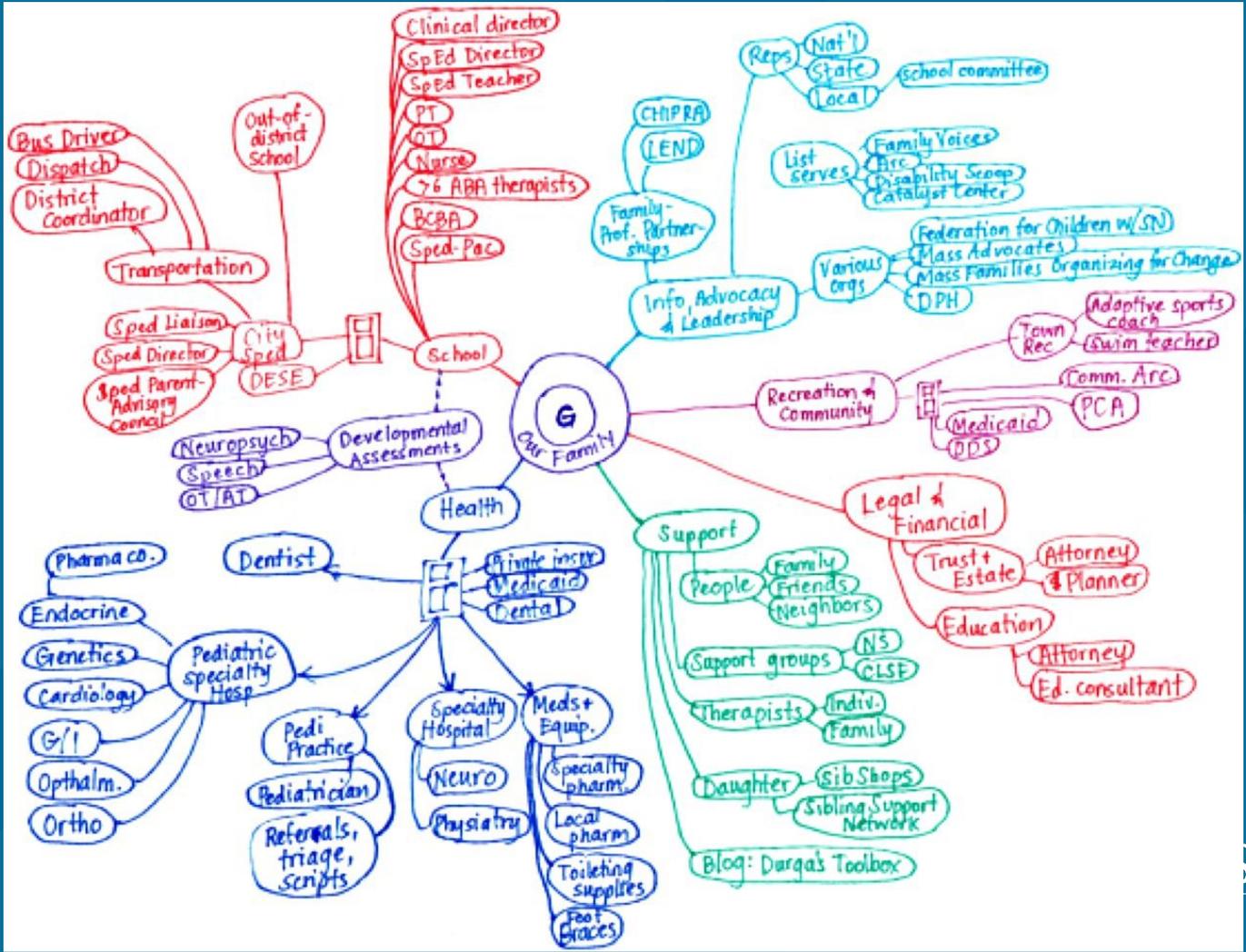
Impacts of COVID

- Access to care
- Access to support services
- Mask wearing
- Limited peer interactions/school opportunities
- Language and social development?
- Parental stressors



Resources

- First 5 – Healthy Development Services
- Rady Developmental Evaluation Clinic (DEC)
- UCSD Developmental-Behavioral Pediatrics
- KidSTART
- San Diego Regional Center
- School District



Take home points

- Early stress and experiences starting prenatally affect attachment, development, and behaviors.
- The family is the patient.
- Early assessment and intervention is critical!

QUESTIONS?

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