Upright Mobility is FUNdamental

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FINANCIAL DISCLOSURE

- **Speaker Name: Ginny Paleg**
- **1. Disclosure of Relevant Financial Relationships**
- I have the following financial relationships to disclose:
  - Consultant for: Prime Engineering
- **2. Disclosure of Off-Label and/or investigative uses**:
- I may discuss BoTox off label use and/or investigational use in my presentation.

2

Why I want you to be in this session today?

- Assistive devices modify the environment to increase/enable participation
- Assistive devices are part of child initiated, caregiver delivered, coached, evidence-based interventions!

3

Have you heard of the "F-Words" in Childhood disability?

Child Care Health Dev. 2012 Jul;38(4):457-63. doi: 10.1111/j.1365-2214.2011.01338.x. Epub 2011 Nov 1.

The 'F-words' in childhood disability: I swear this is how we should think!

Rosenbaum P[1], Gorter JW.

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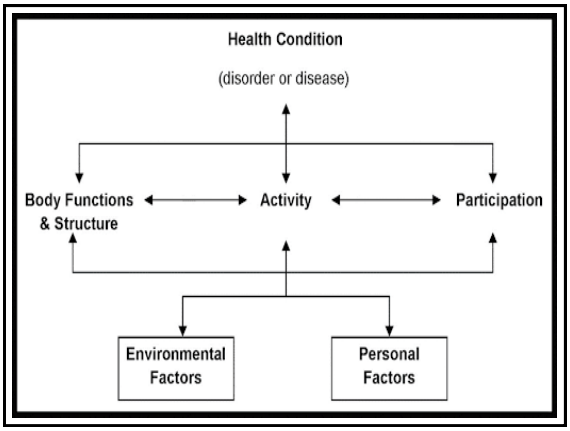

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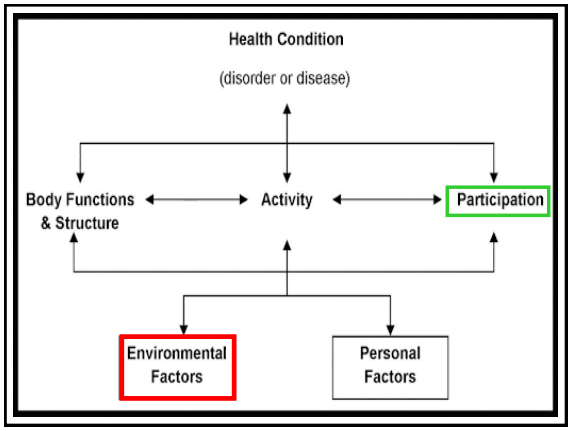

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46 Assistive Technology – Adaptive Equipment	69 Improved independence in self-care [A & P]
	70 Improved computer access [A]
	71 Improved mobility via powered wheelchair [A]
	72 Improved participation [P]
	73 Improved transfers [A]
	74 Reduced caregiver burden [EF]

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Novak, 2020

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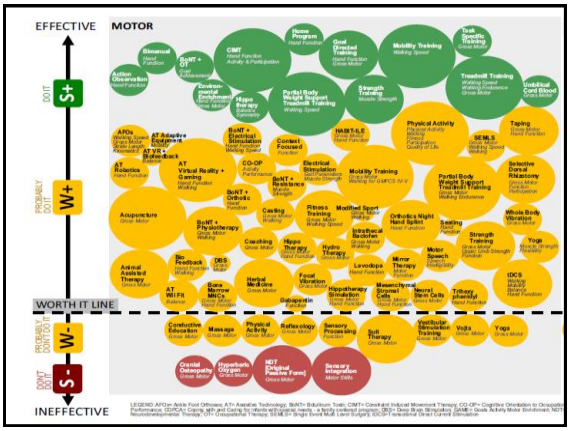

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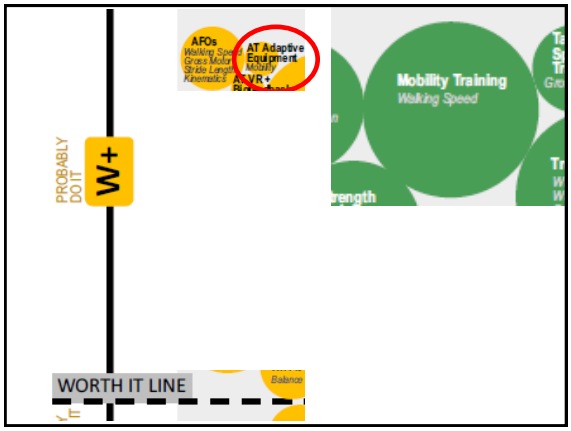

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DEFINITIONS:

- Dynamic Upright Mobility System: Hands-free, ability to reach and interact with the environment, dynamic on three planes, and has large wheels for hand assist. Has option for fixed support at pelvis and trunk in all three planes

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WHO IS THIS FOR?

- Children with motor delays/impairments
- Children with low HINE scores (<40)
- Children with moderate HINE scores (40-60)
- Children with low GMA Motor Optimality scores (<8/10)
- GMFCS III-V
- GMFCS I and II Maybe?

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WHEN?

- When typical children start to explore – 9 months
- When teenager can no longer be efficient and independent in the community with a walker
- When more support leads to more participation in any setting, routine, etc.

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WHEN?

- Gericke, 2006 says 12 months
- Paleg, 2015 says 9 months
- AACPDM Hypotonia Care Pathway says 9 months
- Novak and Morgan say “early weight bearing” (9 months)

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WHERE?

- Home, school. Community, sports, etc.
- Wherever the child is and wants/needs to move

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WHAT?

- Any assistive technology that enables a child to participate in activities and routines
- Starts as assisted, progresses to independent
- MUST be efficient (not too hard)

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MCKEEVER, 2013

- Families prefer hands-free device that enables people to see the child first

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WHO IMPLEMENTS THIS?

- Anyone who is interacting with the child
- Parent, teacher, coach, therapist, physician
- In USA, MD writes RX, gives to parent or therapist who gives to DME provider. DME provider assesses and recommends products
- Therapist usually writes Letter of Medical Necessity focusing on benefits of equipment to activities of daily living (in the home) and highlighting negative consequences of not receiving this equipment
- Usually you must include why lower cost items wont work
- DME person gets MD to sign letter and submits all the paperwork to the third party payor
- ALWAYS APPEAL DENIALS!!! And report to your state insurance commission

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WHY?

- It is a human right to move
- Assistive technology is provided under IDEA
- Independent Mobility can be considered FAPE

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Global Cooperation on Assistive Technology - About us

WHO

Mission

To assist Member States to improve access to assistive technology as a part of Universal Health Coverage.

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Time to stand up and fight for a person's right to move!

https://www.who.int/phi/implementation/assistive_technology/phi_gate/en/

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MOBILITY MAKES YOU SMARTER

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Vision

- Being upright improves vision

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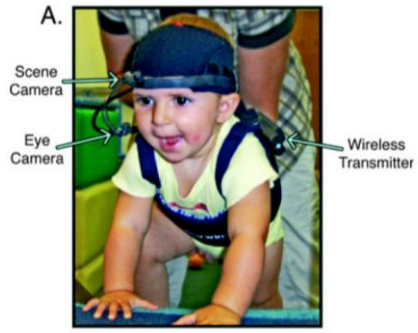
Stimulate vision



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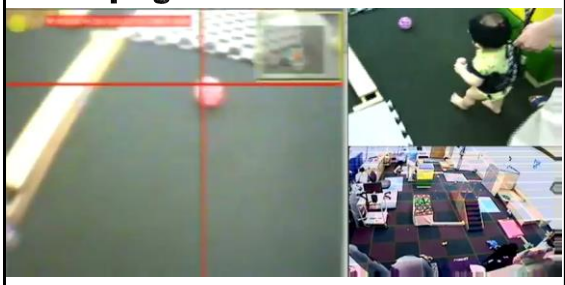
Vision is better when child is upright



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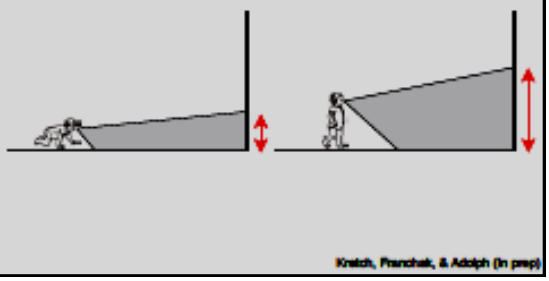
Highest Point Visible



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Movement Starts Early! Video is at 9 weeks!

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46 Football Fields/Day Over 14,000 steps a day (Adolph, 2012)

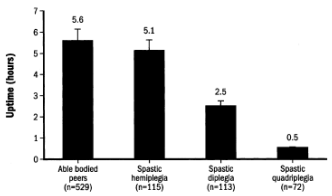
(and they fall 100x/day when they are learning to walk!)

29

Kristie Bjornson, PhD, PT Seattle Children's Hospital

Phys Ther. 2007 Mar;87(3):248-57. Ambulatory physical activity performance in youth with cerebral palsy and youth who are developing typically.

- **What Are They Really Doing?** Dev Med Child Neurol. 2008 Mar;50(3):166
- **Physical Activity Measurement in Cerebral Palsy** Pediatr Phys Ther. 2008 Fall;20(3):247-53.



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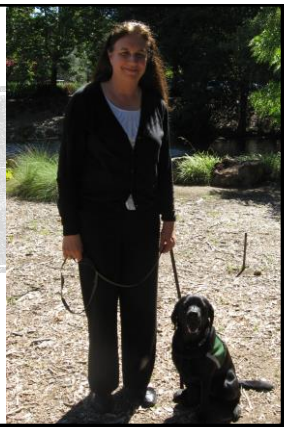
Kermoian R, Campos JJ Locomotor experience: a facilitator of spatial cognitive development 1988 Child Dev. Aug;59(4):908-17.



Dr. Kermoian From Stanford

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Study Design

- All babies 8.5 months old
- Randomly assigned to baby walker 15 min 2x/day or no walker
- Pairs were matched for chronological age and developmental age

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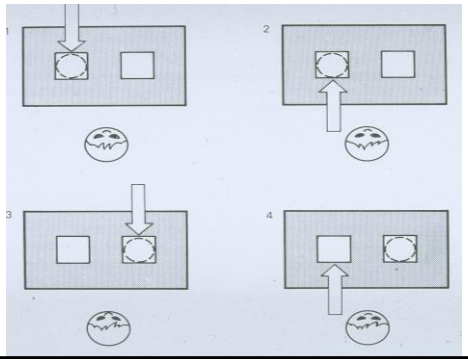
Testing Procedure



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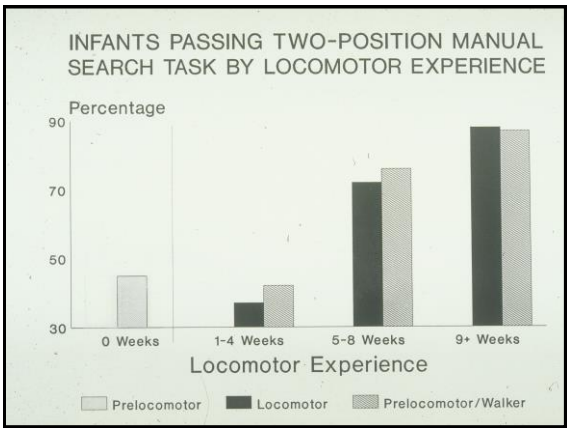

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MOTIVATION

- This study motivated her to give augmented hands free mobility to infants with disabilities
- Being attached to another person is not good enough…

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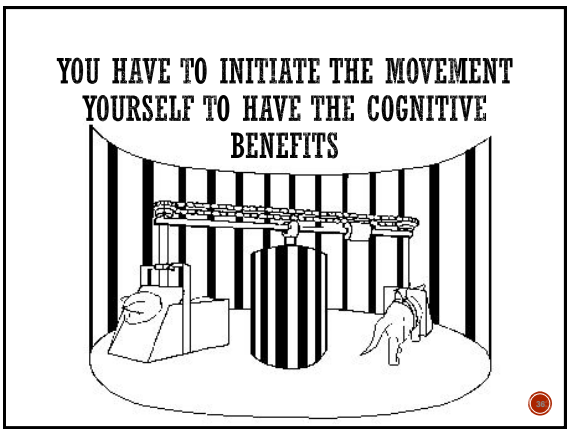

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THE "KITTEN CAROUSEL" EXPERIMENT (HELD & HEIN, 1963)

- The objective of this study was to investigate the role of experience in perceptual-motor development. Kittens were kept in the dark for a period of eight weeks from birth except for an hour per day when they were kept in a 'Kitten Carousel'. The kittens were given appropriate names. 'Passive Kitten' and Active Kitten' were their names. The Active Kitten was given the ability to move freely at it's own discretion when in the kitten carousel. As he propelled himself though space, visual experience tied to his motions occurred. The Passive Kitten received an equal amount of visual experience but these experiences were not related to movements the Passive kitten made. Both Kittens were later released into the light. The Passive Kitten showed no evidence of perceiving depth. The Active Kitten was indistinguishable from normally raised kittens.

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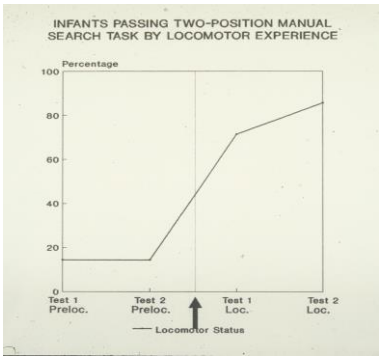
Infants with Spina Bifida



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Anderson, 2013

- Infants who are delayed in the onset of locomotion for neurological or orthopaedic reasons have also been shown to be delayed in the development of spatial-cognitive skills.
- Cognitive deficits in older children and adults with motor disabilities might be attributable to a lack of locomotor experience or delays in locomotor experience, especially if sensitive periods are missed.

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Foreman, 1990

- Children who walked independently or directed the experimenter while being pushed in the wheelchair performed most successfully on the task.
- Control over decision making was the crucial determinant of spatial search performance, not the means by which locomotion was achieved.
- Child has to be able to move efficiently on their own – if walker is too effortful – use a gait trainer!!!!

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Campos, 2009

- The test was a two-position hiding task in which a toy was hidden only in one location, with a second hiding location serving as a distractor.
- Infants were tested monthly after recruitment until 2 months after the delayed onset of independent locomotion, which occurred at 8.5, 11.5, and 13.5 months-of-age in three of the infants and 10.5 months-of-age in the other four.
- Dramatic improvements on the task were noted following the onset of locomotion.
- Infants searched successfully for the hidden object on only 14% of trials before they were able to crawl, but improved to 64% correct search following the delayed onset of locomotion.

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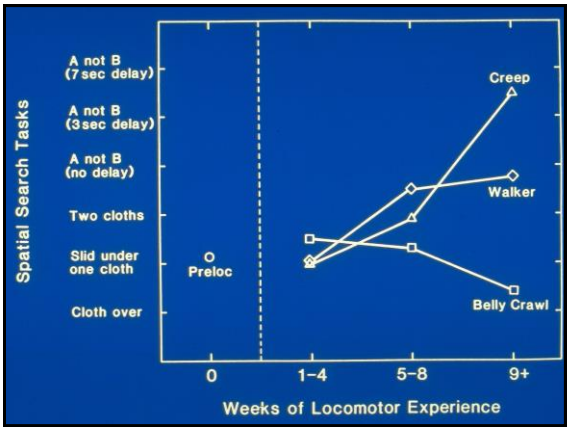

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Belly Crawling is not helping vision or cognition

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From Anderson, 2013

- Kermoian and Campos (1988) argued that belly crawlers failed to profit from their locomotor experiences because belly crawling is so effortful and inefficient.
- Belly crawlers were thought to devote so much effort and attention to organizing forward progression that they were unable to deploy attention to the environment in the same way as the hands-and-knees crawlers and infants in walkers.
- Consequently, the belly crawlers may not have noticed some of the important spatial transformations during crawling, such as occlusion and reappearance of objects that contribute to improved search performance

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Why Do We Want to Push the Big Wheels With Our Hands?

- Our hands get better when we use them, our feet get better when we use our hands! (CIMT, HABIT and HABIT-LE)

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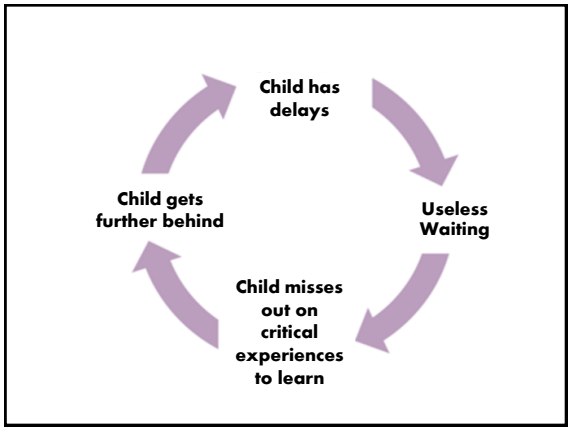

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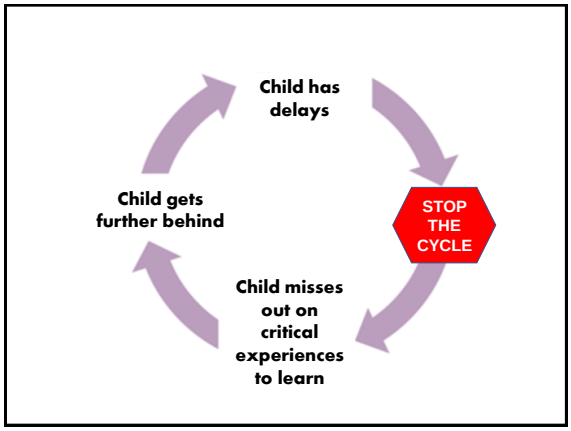

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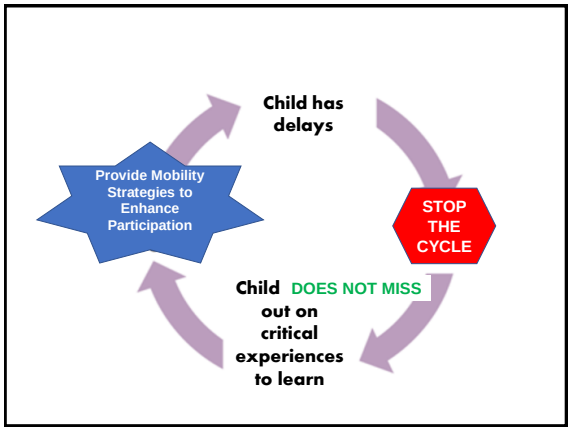

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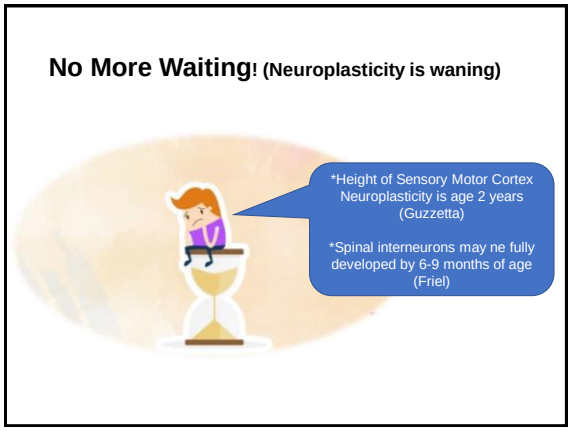

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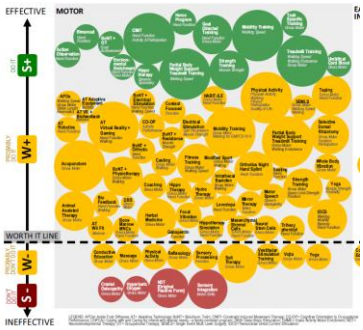
NEXT PICK AN EVIDENCE BASED INTERVENTION! (NOVAK, 2020)



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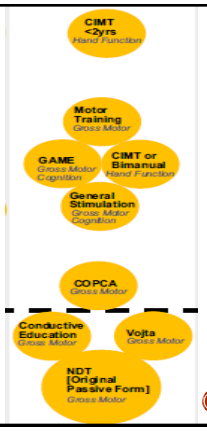
FOR EARLY INTERVENTION TOO!



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WHEN DO KIDS WITH CP GET INDEPENDENTLY MOBILE?

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GMFCS II

When do they get independent mobility?

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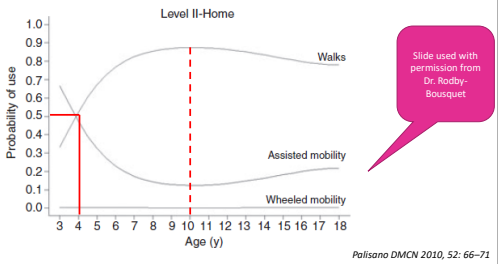
Independent or assisted mobility, GMFCS II



Slide used with permission from Dr. Rodby-Bousquet

Palisano DMCN 2010, 52: 66–71

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GMFCS III

When do they get independent mobility?

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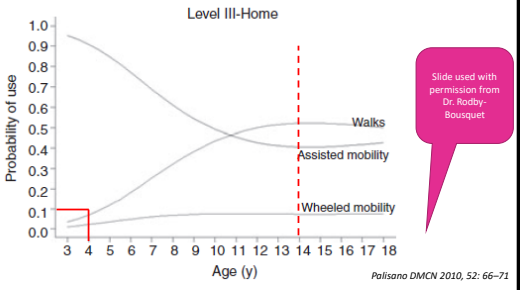
Independent or assisted mobility, GMFCS III



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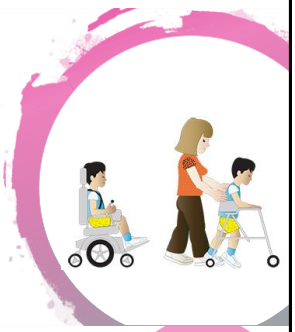
G M F C S I V

When do they get independent mobility?



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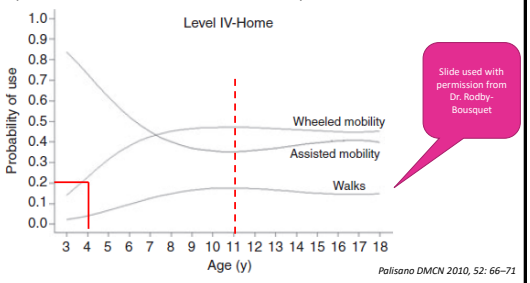
Independent or assisted mobility, GMFCS IV



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WHICH KIDS ARE RIGHT?

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ARTHROGRYPOSIS

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Premature Aging in CP

Mark Peterson, orthopedic surgeon
University of Michigan

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ORIGINAL RESEARCH

Greater Adipose Tissue Distribution and Diminished Spinal Musculoskeletal Density in Adults With Cerebral Palsy

Mark D. Peterson, PhD, MS,[a] Peng Zhang, PhD,[b,c] Heidi J. Haapala, MD,[a] Stewart C. Wang, MD, PhD,[b,c] Edward A. Hurvitz, MD[a]

From the [a]Department of Physical Medicine and Rehabilitation; [b]Department of Surgery; and [c]Morphomic Analysis Group, University of Michigan, Ann Arbor, MI.

Abstract

Objectives: To examine differences in adipose tissue distribution, lumbar vertebral bone mineral density (BMD), and muscle attenuation in adults with and without cerebral palsy (CP), and to determine the associations between morphologic characteristics.

Design: Cross-sectional, retrospective analyses of archived computed tomography scans.

Setting: Clinical treatment and rehabilitation center.

Participants: Adults (N=352) with CP (age, 38.8±14.4y; body mass, 61.3±17.1kg; Gross Motor Function Classification System levels, I–V) and a matched cohort of neurotypical adults. Of the 41 adults with CP included in the study, 10 were not matchable because of low body masses.

Interventions: Not applicable.

Main Outcome Measures: Computed tomography scans were assessed for visceral adipose tissue (VAT) and subcutaneous adipose tissue (SAT) areas, psoas major area and attenuation in Hounsfield units (Hu), and cortical and trabecular BMDs.

Results: Adults with CP had lower cortical (β=−63.41 Hu, $P<.001$) and trabecular (β=−42.24 Hu, $P<.001$) BMDs and psoas major areas (β=−374.51mm², $P<.001$) and attenuation (β=−9.21 Hu, $P<.001$) after controlling for age, sex, and body mass. Adults with CP had greater VAT (β=394.81mm², $P<.001$) and SAT (β=4615.68mm², $P<.001$). Muscle attenuation was significantly correlated with trabecular ($r=.51$, $P=.002$) and cortical ($r=.46$, $P<.01$) BMD, whereas VAT was negatively associated with cortical BMD (β=−.057 Hu/cm², $r^2=.13$, $P=.03$).

Conclusions: Adults with CP had lower BMDs, smaller psoas major area, greater intermuscular adipose tissue, and greater trunk adiposity than neurotypical adults. VAT and cortical BMD were inversely associated.

Archives of Physical Medicine and Rehabilitation 2015;96:1828-33

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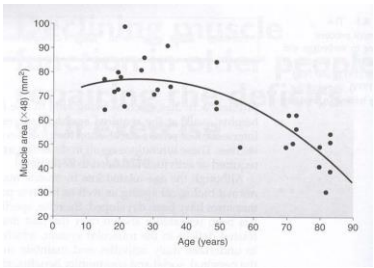
Changes in Muscle Mass with Aging



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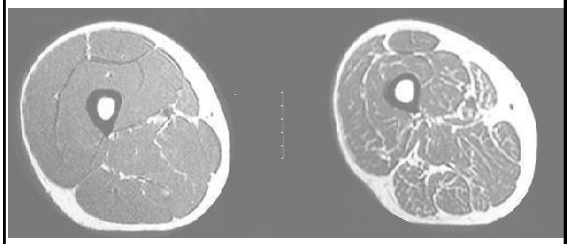
Age and Muscle "Quality"



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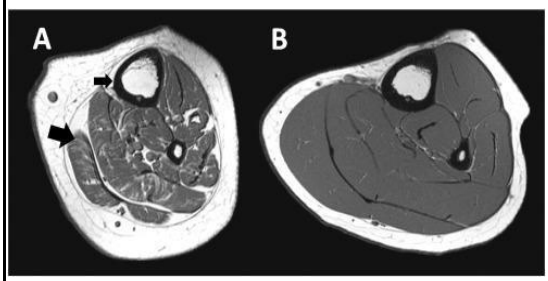

T1-weighted MRI from the mid-tibia demonstrate the marked deficit in bone architecture and muscle volume and the high infiltration of fat with and around the musculature in an ambulatory boy with mild CP (A) compared to a typically developing boy with the same tibia length (B).

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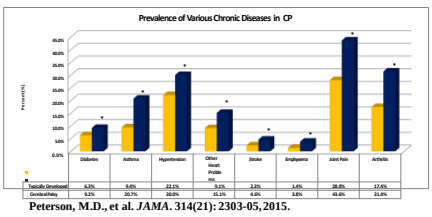
Critical Clinical Question

- **Given the documented loss/absence of lean body mass (muscle and bone), and increased storage of visceral and muscular adipose tissue, is there an increased risk for chronic diseases in CP?**



Peterson, M.D., et al. *JAMA*. 314(21): 2303-05, 2015.

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Other Significant Covariates

Additionally:

- Age (OR: 1.05-1.07)
- **Obesity (OR: 1.07-4.37)**
- Degree of physical disability (OR: 1.49-4.21)
- **Physical inactivity (OR: 1.02-1.25)**

Were each independently associated with greater odds of the 8 chronic diseases

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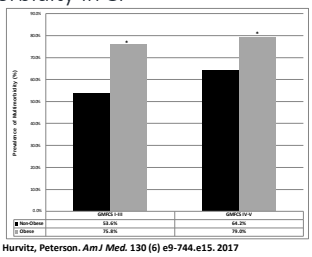
Multimorbidity in CP



Cremer, Hurvitz, Peterson. *Am J Med.* 130 (6) e9-744.e15. 2017

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What's Happening?

- Contemporary jargon:
  - Accelerated aging
  - Premature frailty phenotype
  - Normal weight obesity
  - Exaggerated sedentariness

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Put It All Together

- Moving your muscles grows your brain and muscle
- When you don't move you die
- You have to do this before age 2 to get the best results
- If you move early you be healthier later and not die
- Wanna live and have less pain and depression? Move

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BMJ Case Reports

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BMJ Case Reports 2017; doi:10.1136/bcr-2017-220756

Novel treatment (new drug/intervention; established drug/procedure in new situation)

CASE REPORT

Use of a dynamic gait trainer for a child with thoracic level spinal cord injury

OPEN ACCESS

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There's been a big change….

- No more hands on or passive interventions
- Everything has to be child active
- A mobility device is listed under participation and environmental modification in the ICF
- Mobility is a right

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TAKE HOME MESSAGES

- Dynamic Upright Mobility Systems work and are used as part of evidence-based practice patterns
- Our kids deserve to move
- Moving has lifelong medical consequences
- It's Fun!

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Can we Talk? (ginny@paleg.com)
Follow me on twitter @ginnypaleg