Acknowledgments

1) AACPDM 69th Annual Meeting | October 21-24, 2015

2) Presentations and Workshops:

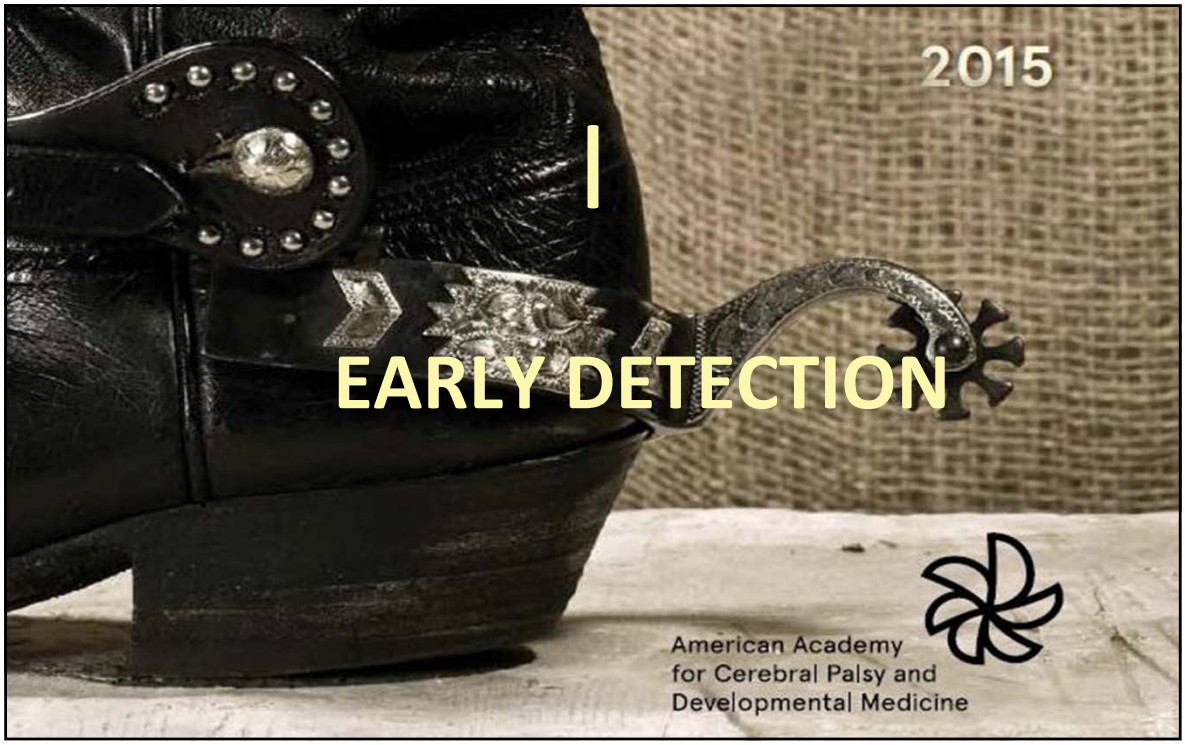
– *Starting Early: Early Intervention Concepts, Strategies and Delivery of Therapy for Infants in the First Two Years*: Julie Linebach, Melissa Tally, Elizabeth Willig-Kroner, Cincinnati Children's Hospital Medical Center, The Aaron W. Perlman Center

– *Early Detection and Early Intervention for Cerebral Pasy*, Cathy Morgan, Iona Novak, Alicia Spittle, Linda Fetters, Cerebral Palsy Alliance, The University of Notre Dame, Murdoch Children's Research Institute, USC, Australia

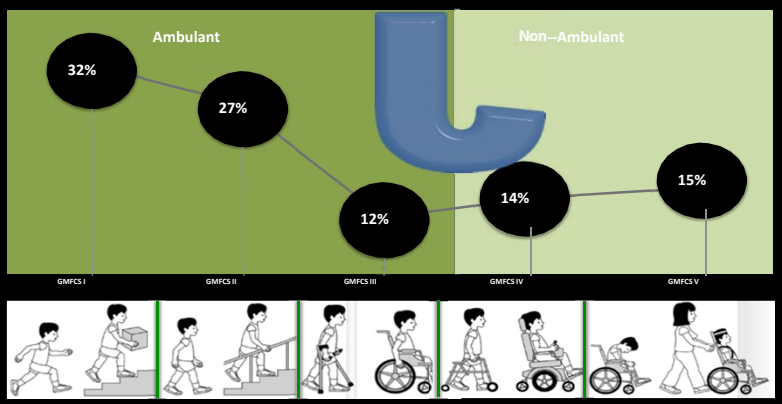
– *Update on Molecular Therapy for Pediatric Neuromuscular Disease*: Jerry R Mendell, Linda Lowes, Lindsay Alfano, Kate Berry, Center for Gene Therapy Nationwide Children's Hospital

OBJECTIVES

- New evidence supporting early intervention for the high risk infant for CP from birth to two years and the potential to maximize outcomes.
- Engage parents in goal setting and high value interventions.
- The importance of child-centered therapy within an enriched environment.



Novak, 2012; ACPR, 2013; RCH



Odwh#G ldj qrvlv

19 Months

More severe diagnosed earlier

n=1734 | Australian Cerebral Palsy Register [NSW/ACT] (2011)

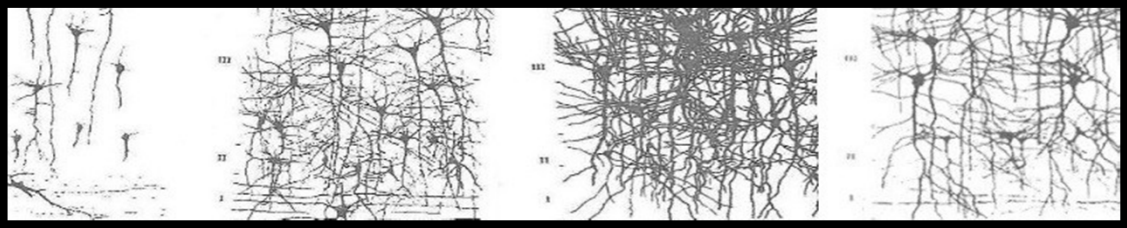
Why Early Intervention?

Limited experiences may cause long-term deficits

- Capitalize on increased neural- plasticity during critical period
- Most neural connections are established by 3 years of age
- Pathways are established and strengthened through repetition and practice

Minimal intervention within "critical period"

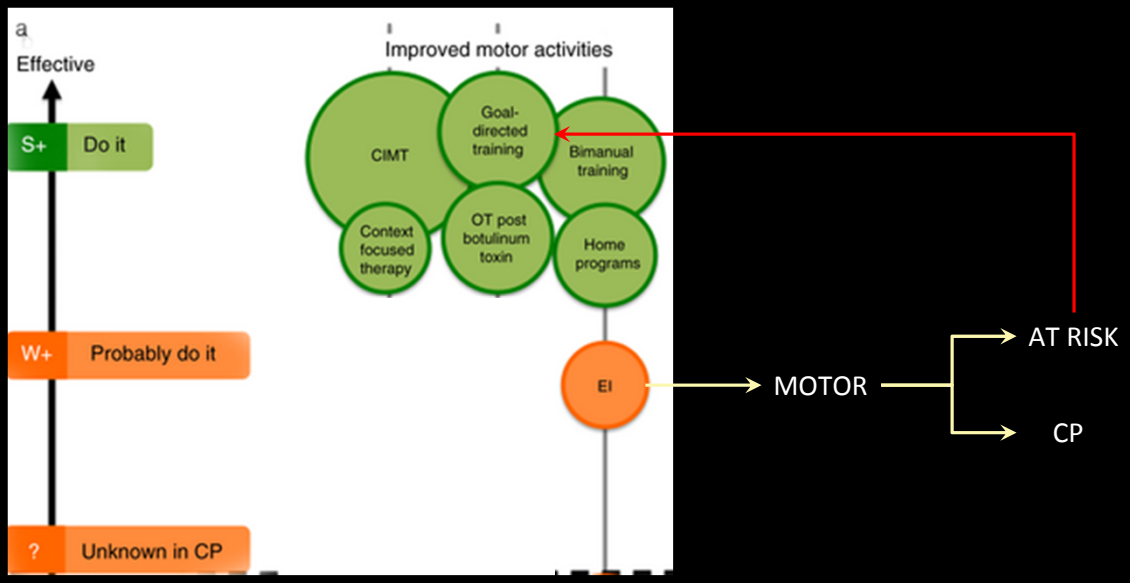
NEWBORN 3 months 24 months 6 year old



EARLY INTERVENTION

Specific interventions should be applied very early rather than delivering general early intervention

Morgan, Catherine, et al. "Optimising motor learning in infants at high risk of cerebral palsy: a pilot study." *BMC pediatrics* 15.1 (2015): 30.



Novak, Iona, et al. "A systematic review of interventions for children with cerebral palsy: state of the evidence." *Developmental Medicine & Child Neurology* 55.10 (2013): 885-910.

Key Concepts Supported by Research:

J. Child Neurol. 2014 Aug;29(8):1141-56. **Evidence-based diagnosis, health care, and rehabilitation for children with cerebral palsy.** Novak I

- A diagnosis is an important step to helping a family access parental support and evidence based information to help their child
- **It is ethically prudent to recommend early intervention even if not sure of diagnosis**
- Best practice-paradigm: child actively participating in real-life task in real-life environment
- Early environmental and task modification to accommodate disability and promote inclusion and independence
- Manage comorbidities of complex diagnosis
- Services framed by the child and family's goals are considered best practice

Key Concepts Supported by Research:

Phys Ther 2010 Dec;90(12):1868-80. **Opportunities for early intervention based on theory, basic neuroscience, and clinical science.** Ulrich BD

- We are missing the boat on opportunities for infants with motor disabilities.
- Young babies create adaptive, goal-directed movements and demonstrate systematic learning from experiences
- Change happens with self-organized interaction, goal directed and repetitive actions within context
- Activity based interventions can be administered by caregivers and guided by therapists

Key Concepts Supported by Research:

Dev Disabil Res Rev. 011;17(2):114-29. **Cerebral palsy--don't delay.** McIntyre S, Morgan C, Walker K, Novak I.

- It is the responsibility of the health care professional who observed major risk factors or a motor delay to investigate further, diagnose at risk CP early, and refer to early intervention to optimize cognitive function
- Refer for intervention when an infant is at high risk without a formal diagnosis
- Delaying diagnosis can worsen parental depression and stress
- All children with suspected injury should have MRI imaging
- Qualitative assessment of general movements are predictive of CP. Routinely used neuro observations and standardized developmental tests are not designed to detect CP.

International Clinical Guideline for Early Detection and Intervention for High Risk of Cerebral Palsy

IMPACT for Cerebral Palsy

Cerebral Palsy ALLIANCE

CanCHILD MacMaster

Key Ingredients:

- Shared goal-setting
- Activity-based intervention
- Routine-based practice
- Enriched environment

Specific Strategies:

Engaging Parents

- Therapy to support early parent-infant relationships
- Build parent confidence
- Education and training
- Build opportunities for practice
- Incorporate into daily routines

Building Enriched Environments

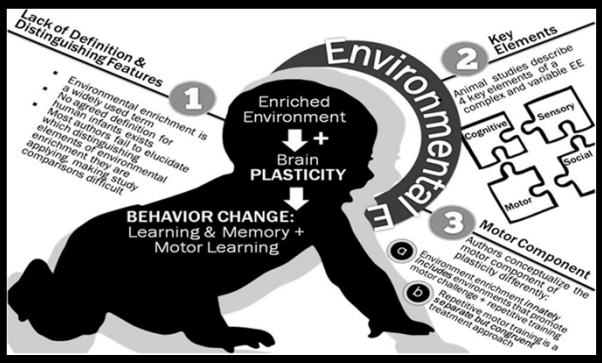
- Adapt access to play, play is FUN!
- Stimulate exploration, inquiry and learning
- Enrich for cognitive, motor, sensory and social development

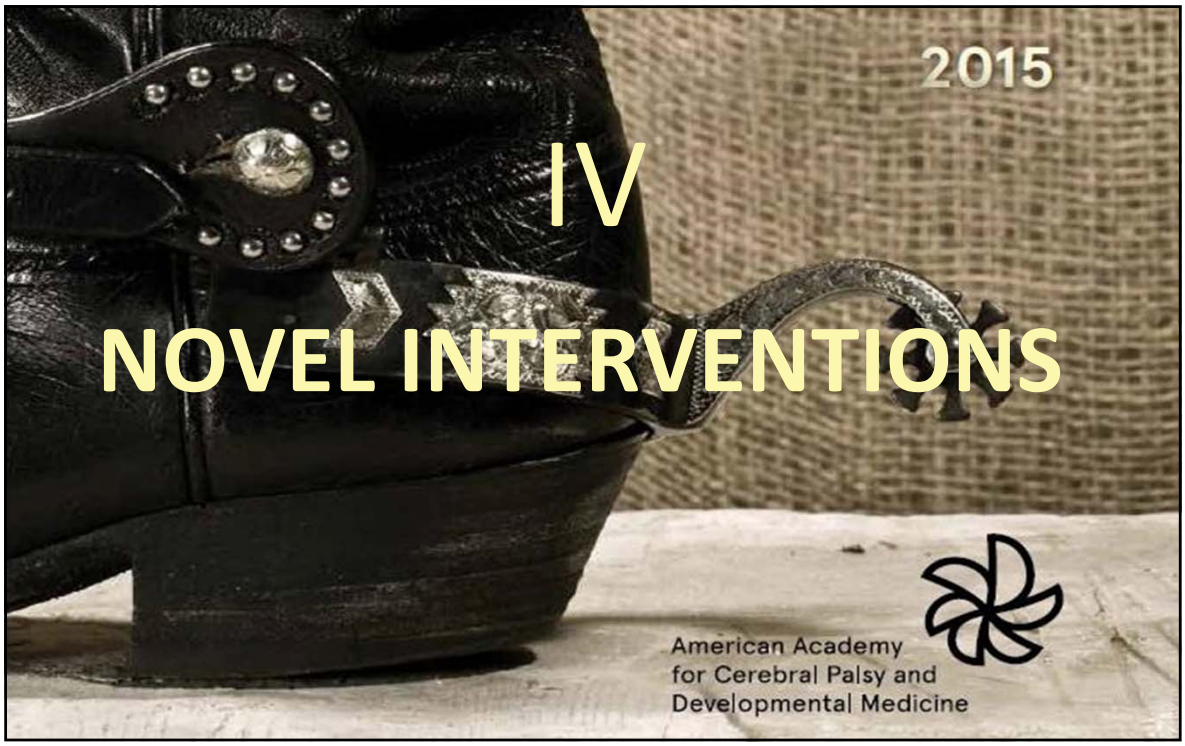
Applying Early Motor Learning

- Goal-oriented intensive motor training (Morgan et al., 2015)
- Build in repetition
- Scaffold so infant is able to complete at least part of the task
- Experience-based activities will engage self-initiation of movement
- Occurs while participating in daily routines (ie., at the grocery)

Key Concepts Supported by Research:

Pediatrics. 2013 Sep;132(3):e735-46. **Enriched environments and motor outcomes in cerebral palsy: systematic review and meta-analysis.** Morgan C, Novak I, Badawi N





Infant Exploratory Learning

Discover the Contingency

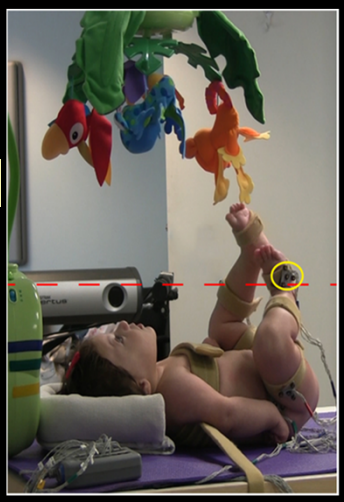


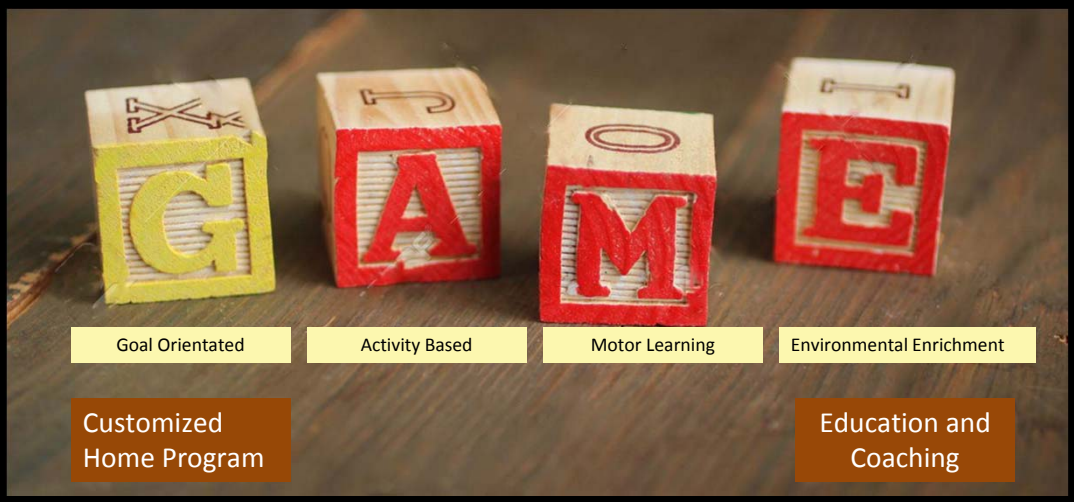
Exhibit more selective hip-knee coordination

Sargent, Barbara, et al. "Infant exploratory learning: Influence on leg joint coordination." *PloS one* 9.3 (2014): e91500. APA

Augmenting Muscle Activation

DUFF, S., et al. "Self-generated feedback to increase muscle activation in children. (2015)"

GAME Intervention



Morgan, Catherine, et al. "Optimising motor learning in infants at high risk of cerebral palsy: a pilot study." *BMC pediatrics* 15.1 (2015): 30.

APA

Key Concepts Supported by Research:

Morgan et al. BMC Pediatrics (2015) 15:30. Optimizing motor learning in infants at high risk of cerebral palsy: a pilot study Catherine Morgan, Iona Novak, Russell C Dale, and Nadia Badawi

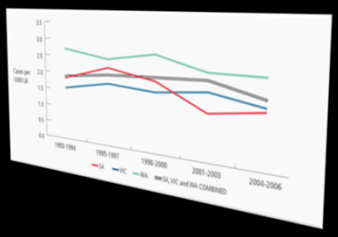
- GAME (Goals- Activity- Motor- Enrichment) appears to offer a promising and feasible new motor intervention for CP.
- Parents coached in simple motor task analysis and appropriate strategies to enhance development and in setting up motor enriched environments
- Favorable short-term motor outcomes were noted in standardized testing of motor ability
- Parents reported improvements in the COPM performance and satisfaction
- Important to monitor parents well-being due to higher depression and anxiety levels more than parents with children without disabilities

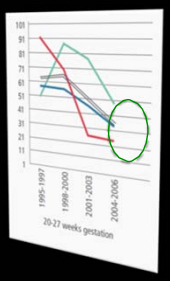
Key Concepts Supported by Research:

Morgan et al. BMC Neurology 2014, 14:20 GAME :protocol of a single RCT of motor training, parent education and environmental enrichment for infants at high risk of cerebral palsy Catherine Morgan, Iona Novak, Russell C Dale, Andrea Guzzetta and Nadia Badawi

- RCT of a goal driven, motor learning approach with environmental interventions and parent education
- Set goals with family, educate parents, enrich the environment
- "standard care"- varied approaches to therapy intervention including neurodevelopmental therapy, developmental skills approach, group therapy or motor learning approaches
- Outcome measures: PDMS-2, GMFM, COPM,AHEMD-IS, DASS, BSID-III

Until 2015 Total Rate has been Stable BUT





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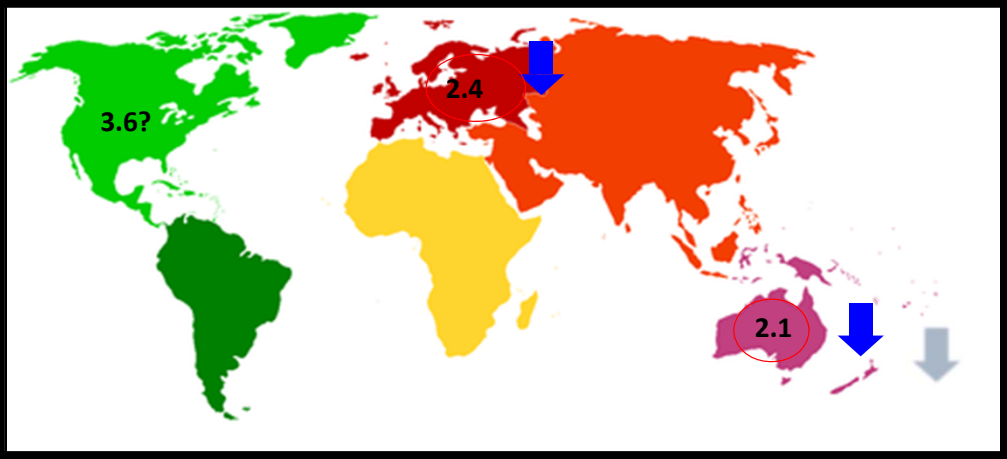
Vxcskdwh

Sellier, Elodie, et al. "Decreasing prevalence in cerebral palsy: a multi-site European population-based study, 1980 to 2003." *Developmental Medicine & Child Neurology* 58.1 (2016): 85-92.

CEREBRAL PALSY RATES

2.1/1000



Oskoui 2013; ACPR 2013; Glinianaia 2011; Himmelmann 2014; SCPE 2000; Yeargin--Allsopp 2008

Cerebral Palsy Registry

BIG SHOUT OUT!!

We are creating a national registry of information about children with cerebral palsy.

SUNNY HILL HEALTH CENTRE FOR CHILDREN
An agency of the Provincial Health Services Authority

Diane Wickenheiser

BC Project Coordinator
604-453-8300 ext. 8482
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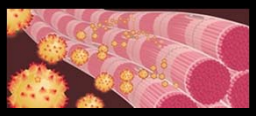

Molecular Therapy for Pediatric Neuromuscular Disease

Exciting Results for 2015

Phase I Clinical Trial in SMA type 1
Phase IIB trial using Eteplirsen for DMD

Mendell, Jerry R., et al. "Eteplirsen for the treatment of Duchenne muscular dystrophy." *Annals of neurology* 74.5 (2013): 637-647.
Meyer,Kathrin; Ferraiuolo,Laura; Schmelzer,Leah; Braun,Lyndsey; McGovern,Vicki; Likhite,Shibi; Michels,Olivia;

Govoni,Alessandra; Fitzgerald,Julie; Morales,Pablo; Foust,Kevin,D; Mendell,Jerry,R; Burghes,Arthur,HM; Kaspar,Brian,K. 2015. Improving Single Injection CSF Delivery of AAV9-mediated Gene Therapy for SMA: A Dose-response Study in Mice and Nonhuman Primates. *MOLECULAR THERAPY*. Vol. 23, no. 3. (March): 477-487.

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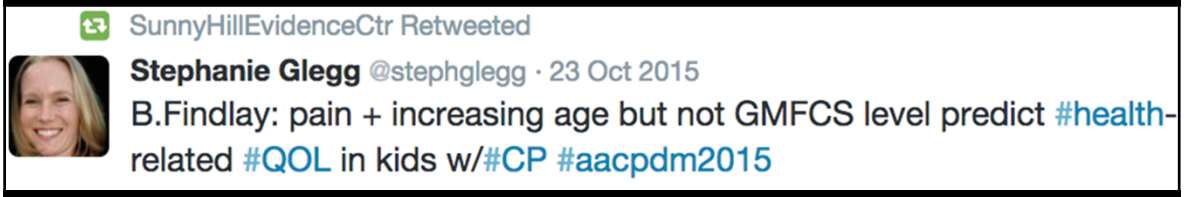
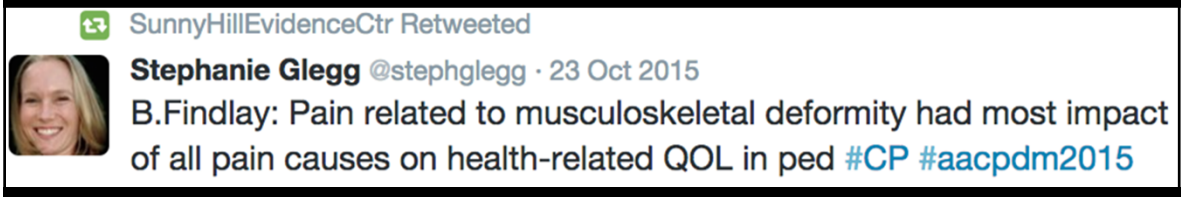
Pain and quality of life





Pain and QOL

SunnyHillEvidenceCtr Retweeted

Sunny Hill Feeding @shfeeding · 23 Oct 2015

Hip health important at skeletal maturity to reduce pain and improve QOL. Hip surveillance associated with better hip morphology #aacpdm2015

'Green Light' Interventions for CP

Review

A systematic review of interventions for children with cerebral palsy: state of the evidence

FREE

Iona Novak[1,2,*], Sarah Mcintyre[1,2], Catherine Morgan[1,2], Lanie Campbell[2], Leigha Dark[1], Natalie Morton[1], Elise Stumbles[1], Salli-Ann Wilson[1] and Shona Goldsmith[1,2]

Article first published online: 21 AUG 2013

DOI: 10.1111/dmcn.12246

Issue

Developmental Medicine & Child Neurology

Volume 55, Issue 10, pages 885–910, October 2013

Interventions for CP

SunnyHillEvidenceCtr Retweeted

Stephanie Glegg @stephglegg · 23 Oct 2015

L.Fetters: #CP needs early diagnosis & treatment incorporating exploratory learning, w/ child as agent #aacpdm2015

SunnyHillEvidenceCtr Retweeted

Stephanie Glegg @stephglegg · 23 Oct 2015

Promote active movement initiated & executed by the child, problem-solving, practice w/ success/failures #aacpdm2015 #CerebralPalsy

Telehealth for rehabilitation

Cincinnati Children's Center

SunnyHillEvidenceCtr Retweeted

Stephanie Glegg @stephglegg · 23 Oct 2015

Design Thinking Model for #telerehab facilitates care coord, family educ/coaching, home Ax/mods, interactive gaming & followup #aacpdm2015

Design Thinking:

- Family readiness/ableness
- Ideation & conceptualization process
- Prototyping/piloting (QI collaboration)
- Implementation & spread

Telehealth considerations

SunnyHillEvidenceCtr Retweeted

Stephanie Glegg @stephglegg · 23 Oct 2015

J.Long/K.Harpster: Primary telerehab barriers: Regional licensing, funding reimbursement, connection issues re network & devices #aacpdm2015

IC21

Novak

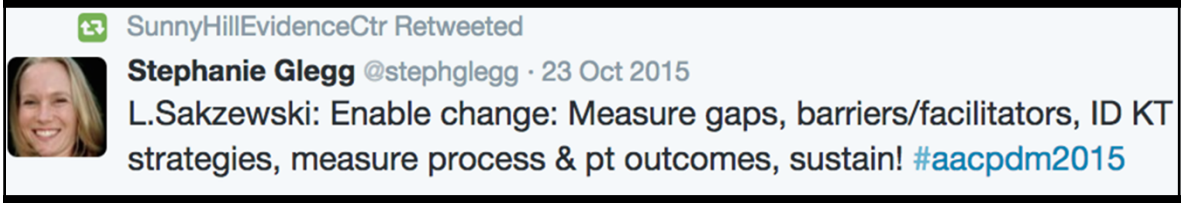
Evidence informed health care

SunnyHillEvidenceCtr Retweeted

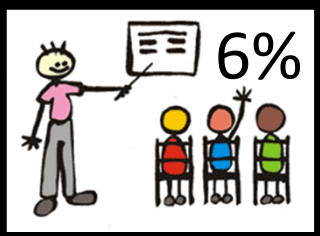
Stephanie Glegg @stephglegg · 23 Oct 2015

10-20yr research to practice gap; 10-40% of patients don't receive proven effective txs. 20%+ receive ineffective/harmful txs #aacpdm2015

Steps for practice change



Identify KT strategies



Supporting practice change

SunnyHillEvidenceCtr Retweeted

Stephanie Glegg @stephglegg · 23 Oct 2015

Engaging parents & media to engage health professionals to change practice - green light KT intervention #aacpdm2015

Supporting practice change

SunnyHillEvidenceCtr Retweeted

Stephanie Glegg @stephglegg · 23 Oct 2015

L.Sakzewski: Prac change sustainability via mgr support, prac process change, stakeholder engagement in plans, research partic'n #aacpdm2015

SunnyHillEvidenceCtr Retweeted

Stephanie Glegg @stephglegg · 23 Oct 2015

L.Sakzewski: Enhance KT sustainability w/ doc templates, ongoing educ, planning, mentoring, communic'n, audit/feedback #aacpdm2015

Implementation

e.g. increased dose

- Less frequent, longer sessions
- Therapy in pairs/groups
- Record home therapy (assess treatment fidelity)
- Structured home program
- Education for families

Treatment fidelity

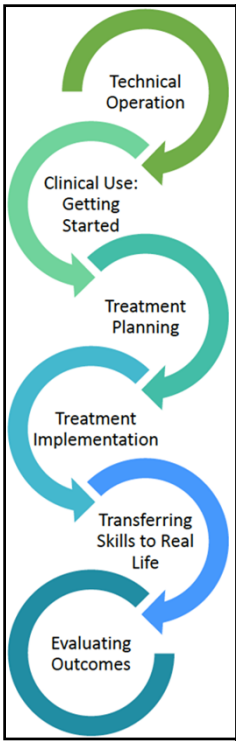
- Measure to explore treatment thresholds, identify inactive ingredients and inform protocol adaptation for clinical practice

ICF Core sets

- Describe level of functioning, facilitators and barriers that influence functioning
- Toolbox of pre-appraised measures
- E-learning modules:

  http://learn.phsa.ca/shhc/icf/

ICF e-tool



Competencies for using virtual reality & active video games for rehabilitation

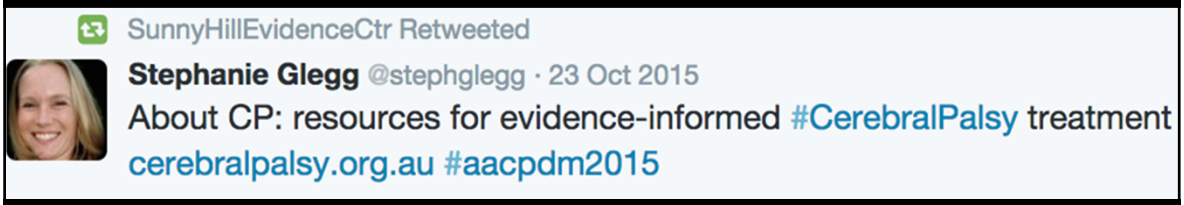
- Applying a motor learning approach
- Resources for clinical application

Stephanie Glegg
sglegg@cw.bc.ca

VR 4 REHAB

VR4Rehab.com

Additional resources



www.childdevelopment.ca => Health Conditions => CP
=> ICF Tool

@SunnyHill_Evid

OBJECTIVES

- Provide an update on evidence related to the hip in children with CP
- Review current evidence for treatment of the upper extremity in children with CP
- Review recommendations for treadmill training

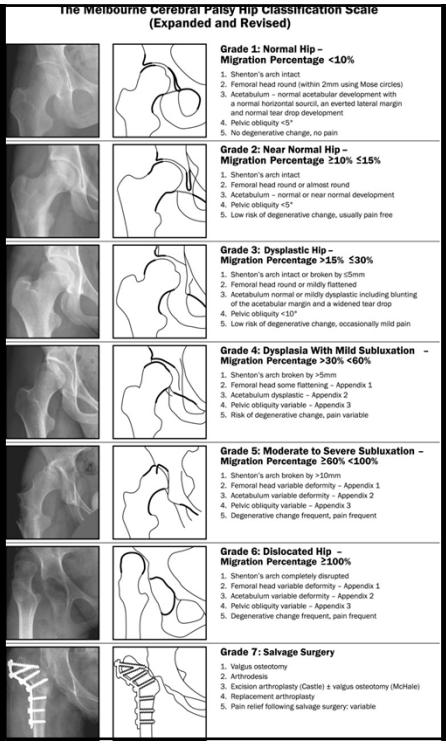
Management of the Hip

Hip Health at Skeletal Maturity

Hip health at skeletal maturity in adolescents and young adults with cerebral palsy. Willoughby K, Thomason P, Wawrzuta J, Molesworth C, Graham K. (2015; 57 (Suppl 5): p. 46)

- Prospective, population based transition clinic
- Population: 367 individuals with CP, born Jan 1990-Dec 1992
- 103 had developed hip displacement
- 98 (95% with hip displacement) participated, mean age 19.8 (15-24 years)
- GMFCS, pain (severity and frequency), hip morphology

Melbourne Cerebral Palsy Hip Classification System (MCPHCS – E&R)



Hip Health at Skeletal Maturity

- Hip Pain associated with GMFCS Level
  - GMFCS I-III median pain score: 2 (1.0-3.0)
  - GMFCS IV/V median pain score: 3 (2.0-5.0) ($p < 0.001$)
- Hip surveillance associated with improved hip morphology and less pain
  - Worse hip morphology (MCPHCS grades VI and VII) had fewer hip radiographs ($p < 0.001$)
  - 14% not under surveillance median pain score: 7 (5.0-8.0)
  - 86% under surveillance median pain score: 2 (1.0 – 3.5) ($p < 0.001$)

Hip Health at Skeletal Maturity

Conclusion:

- Increasing GMFCS levels, combined with limited or no hip surveillance, associated with poor hip morphology and high levels of pain at skeletal maturity
- Adolescents at all GMFCS levels with access to hip surveillance and appropriately timed surgical management had generally satisfactory hip morphology at skeletal maturity and lower levels of pain

Pelvic Obliquity at Skeletal Maturity

Pelvic obliquity in adolescents with cerebral palsy: a population based study of prevalence and long-term consequences. Heidt C, Hollander K, Wawrzuta J, Molesworth C, Willoughby K, Thomason P, Khot A, Graham K. (2015; 57 (Suppl 5): p. 45)

- Presence, prevalence and severity of pelvic obliquity was measured
- Median pelvic obliquity was 4^{o} ($2\text{-}8^{o}$)
- Trend that as GMFCS level increased, pelvic obliquity increased ($p < 0.001$)
- Strong correlation between hip morphology and pelvic obliquity
  - Hip on high side more likely to have higher migration percentage, acetabular index, and worse MCPHCS grade than hip on low side

Pelvic Obliquity at Skeletal Maturity

Conclusions:

- Identification and management of pelvic obliquity is important
- Ambulant adolescents: mild pelvic obliquity associated with hip dysplasia on the high side which is a risk factor for degenerative arthritis
- Non-ambulant adolescents: pelvic obliquity associated with symptomatic hip subluxation/dislocation and scoliosis

Hip Pain and Hip Displacement

Hip pain is more frequent in severe hip displacement; a population-based study of 68 children with cerebral palsy. Ramstad K, Terjesen T. (2015; 57 (Suppl 5): p. 12)

- Population-based study of hip pain
- Born 2002-2006, GMFCS III-V
- 68 children responded (49% of Norwegian CP Follow up Program)
- Mean age 9yrs 2m +/- 1yr 5 m (6yrs 10m – 12 yrs)
- 14 (21%) ITB pumps, 37 (54%) had ortho surgery to improve coverage of femoral head
- Primary caregivers filled out Child Health Questionnaire (CHQ), marked location of recurrent pain on a body map

Hip Pain and Hip Displacement

- 31% of caregivers reported hip pain
- Severe hip displacement (MP >50%) was significantly associated with hip pain (p = 0.01)
- Hip pain more frequent in children
  - With spastic quadriplegia (p=0.04)
  - Who had not undergone hip surgery (0.04)

Conclusions:

- Pain was distributed across the whole range of pain severity
- Pain severity increased with increasing migration percentage
- Surgical correction recommended before MP 50%

II

Upper Extremity

CIMT and Bimanual Therapy

Pediatric constraint induced movement and bimanual therapy implementation into the clinic setting. Harpster K, Garcia Reidy T, Tanner KJ.

Modified-Constraint-Induced Movement Therapy (mCIMT):

- Intervention where constraint is used on the unaffected hand of children with hemiplegia to improve use of their affected hand

Bimanual Therapy

- Intervention to improve two hand function in children with hemiplegia to improve function in tasks that require two hands

Gold standard interventions for improving arm and hand function and independence in daily activities for children with hemiplegia

Cincinnati Children's Hospital Medical Centre Evidence-Based Care Guidelines

Target population:

- >1 year of age
- Unilateral UE impairment(s) associated with neurological conditions (e.g. cerebral palsy, traumatic brain injury, tumor resection, brachial plexus injury, etc.)
- Caregiver able and willing to commit

Exclusions:

- Not able to participate in purposeful play of functional activities
- Contracture(s) significantly limiting arm function
- Dystonia preventing controlled movements by the patient

Cincinnati Children's Hospital Medical Centre Evidence-Based Care Guidelines

Literature says:

- CIMT and BIT at the same intensity were equally as effective in improving hand function
- CIMT showed greater gains in unilateral function while BIT showed greater gains in bimanual function
- Current studies looking at CIMT followed by BIT
- Many questions still to be answered….

Cincinnati Children's Hospital Medical Centre Evidence-Based Care Guidelines

1. Include family self-management education and skill building
2. In-depth education for family to understand the commitment necessary prior to starting
3. Evaluation and treatment by OT or PT trained in mCIMT/BIT principles
4. Initial assessment within 2 months of initiating treatment (standardized assessment tools)
5. Assessment should include 1x measure for individualized patient/family goals, 2x measures for activity (1x unimanual and 1x bimanual)
6. Combo of mCIMT followed by BIT (48-63 hours during an episode of care)

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7. Shared decision making re: protocol selection, method of constraint, home program, need for continued therapy services
8. Treatment: individual or group, based on mCIMT/BIT principles provided
9. Reassess within 1 month for future planning
10. 3 month break recommended between session

III

Treadmill Training

Recommended Treadmill Training Parameters

Ronan S, Bingham E, Mushkat S, Sedman E. Recommended treadmill training parameters for persons with cerebral palsy based on the GMFCS levels: a systematic review. (2015; 57 (Suppl 5): p. 67)

- SR of partial weight bearing (PWBTT) and full weight bearing (FWBTT) treadmill training
- Children with CP less than 21 years
- Articles published January 2007 – March 2014
- 174 articles reviewed; 19 met inclusion criteria
- 13 PWBTT, 6 FWBTT
- GMFCS I – V in PWBTT articles
- GMFCS I- III in FWBTT articles
- Settings: home, schools, clinics
- Protocol lengths: 2 – 12 weeks
- Frequency 2 – 6 days per week, 1-2 times per day

Recommended Treadmill Training Parameters

Outcomes:

- 7 endurance (3 found ss improvements)
- 15 gross motor function (10 ss)
- 14 ambulation outcomes (9 ss)
- 5 balance outcome (3 ss)

Conclusions:

- PWBTT and FWBTT show promise as an effective intervention technique
- Children at GMFCS levels I-IV may benefit from PWBTT
- Children at GMFCS levels I-III may benefit from FWBTT
- Studies need for children GMFCS V
- Heterogeneity of protocol parameters suggest children with CP can make improvements with shorter duration, higher intensity and longer duration, lower intensity programs
- More studies on dosage are necessary