### Translating the Clinical Practice Guideline for Congenital Muscular Torticollis into Parent Education

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### General information about Congenital Muscular Torticollis (CMT)

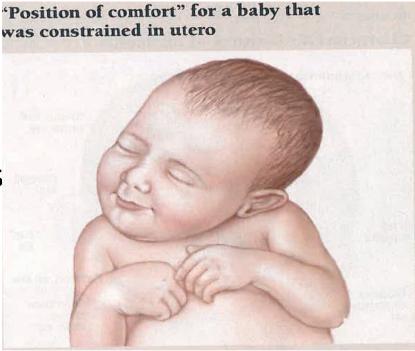
- One in six infants have torticollis (Stellwagen, 2008)
- CMT and plagiocephaly are usually seen together and can influence the treatment and outcomes (vanVlimmeren, 2007)
- Early detection is possible and important
- (Stellwagen, 2008)



#### Pathophysiology and Etiology of CMT (Freed 2004) (Stellwagen 2004)

#### Causes:

- Intrauterine crowding
- Muscle trauma
- Soft tissue compression leading to compartment syndrome
- Congenital abnormalities of the soft tissue of SCM



### Clinical Subgroups of CMT

Cheng et al 2000; Stellwagen, 2004; Clarren et al, 1979, Freed, 2004

Subgroups: Palpable swelling pseudotumor





### SCM (sternocleidomastoid) tightness without tumor



Muscular torticollis without SCM muscle tightness or tumor



### Clinical characteristics of "stuck" baby

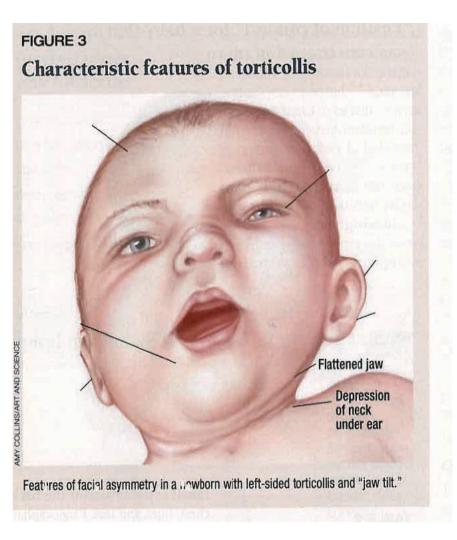
Stellwagen, 2004 Campbell, 2012

#### Ipsilateral side

Eye smaller Cupped ear Flattened lower jawline Elevated shoulder

#### Contralateral side

Flattened ear Mild frontal flattening Tilted mandible

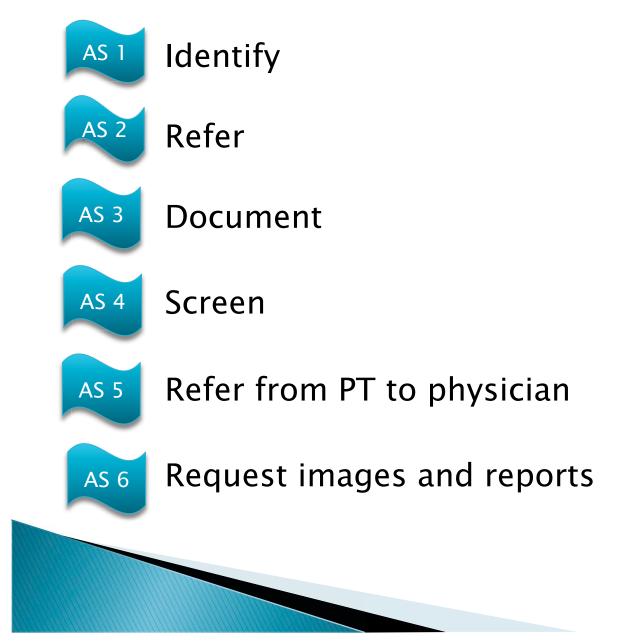


### **Clinical Practice Guideline for CMT**

- Levels of evidence and grades of recommendations
- Action statements divided into 4 sections
- Guideline implementation recommendations
- Summary of research recommendations



### Identification and Referral (1-6)



### Red Flag concerns



- Suspected hip dysplasia (Nuysink, J. et al. 2008)
- Skull/facial asymmetry (Stellwagen, L.et al 2008)
- Atypical presentation (Chen, M-M. et al. 2005)
- Abnormal tone (Tomczak, KK. et a, 2012)
- Late-onset torticollis (Tomczak, KK. et a, 2012)
- Visual abnormalities (Tomczak, KK. et a, 2012)
- History of acute onset (Haque,S. et al.2012; Ballock, RT. et al. 1996)



# Physical Therapy examination of Infants with CMT (7-9)



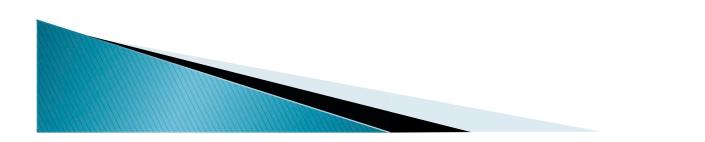
Examination of body structure



Classify the level of severity



Examine activity and developmental status



#### Action Statement 7 Examination of body structures

- Passive ROM
  - Anthrodial
    - Usually requires 2 people
  - Goniometer
    - Usually requires 2 people
  - Visual inspection
  - Photograph
  - Palpation of extensibility



AS 7



#### Lateral Flexion or Side Bending

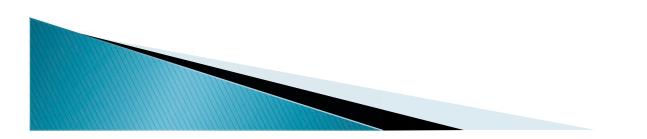


#### Severity of CMT is determined by difference in left and right measurements



#### Passive Cervical rotation (2–10mos)





#### Active ROM



Active cervical lateral flexion

Muscle Function Test (Ohman et al, 2008)







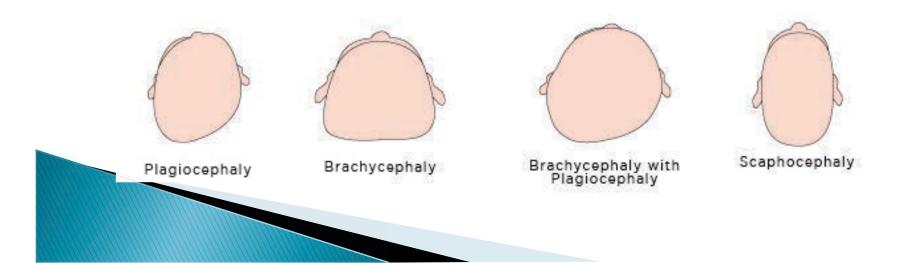
http://torticollis.dinstudio.se/text1\_37.html



## AS 7

#### Pain

- Using the FLACC- Face, Legs, Activity, Crying, and Consolability (Merkel, 2002)
- Skin integrity (Freed, 2004, Gray, 2009)
- Muscle (Cheng, JC-Y. et al 2000)
- Craniofacial characteristics



### Argenta Classification System



- Type I
  - Deformity restricted to back of the head

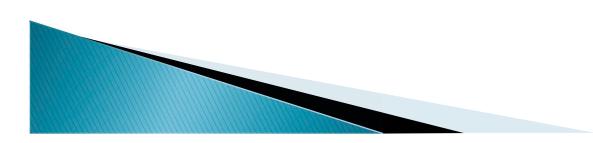
- Type II
  - Deformity includes malposition of ipsilateral ear and posterior flattening
- Type III
  - Includes frontal asymmetry deformity, malposition of ipsilateral ear, and posterior flattening
- Type IV
  - Includes ipsilateral facial deformity, ipsilateral fronal asymmetry, and ipsilateral ear deformity
- Type V
  - Decompression of brain vertically or temporally as well as all above with temporal bulging or abnormal vertical growth of posterior skull

Argenta, 2004



### Other factors with measurements

- Modification or avoiding tests
  - Osteogenesis Imperfecta
  - Congenital Hemivertebra
  - Down Syndrome (if not cleared for cervical instability)





#### 8. Classify the level of severity of CMT

#### Strongest factor of outcome





#### Facts regarding intensity and duration of treatment Petronic, 2010

- Classification Grade
- Access to services
- Patient/Caregiver adherence
- Muscle Tissue Elasticity
- Comorbidities



#### 9. Examine activity and developmental status

- Higher incidence of developmental delays with CMT (Schertz, 2012)
- Delays may be demonstrated as early as 2 months (Ohman, 2009)
- Parental instruction in prone positioning is an important factor in decreasing developmental delays with CMT (Ohman 2009)





#### 10. Examine Participation status Parent/caregiver should be:

Alternating sides in feeding (Losee, JE. et al. 2007.)

Placing infant in supine sleeping positions, alternating which side the infant is positioned (Peitsch, WK et al. 2004)

Limiting time in equipment (Laughlin, J. et al. 2011;Stewagen, LM. Et al. 2004; Boere-Boonekamp, MM. et al. 2001)

Positioning infant in prone while awake and supervised (Ohman et al. 2009; Monson, RM. et al. 2003; Kennedy, E. et al. 2009.)



### Positioning

- Purpose is to:
  - Treat CMT if present
  - <u>Prevent</u> deformation plagiocephaly that can lead to CMT (Stellwagen, L. et al. 2007)
  - <u>Correct</u> positional preferences that can lead to CMT and plagiocephaly (vanVlimmeren, LA. et al. 2008)



## AS 10

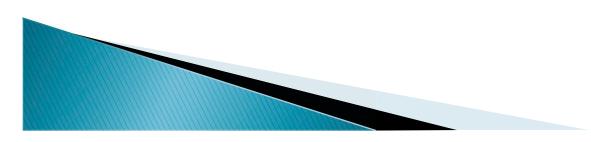
### Positioning

- Positioning is important in its interaction with CMT resolution
  - Prone positioning (for greater than 1 cumulative hour per day) appears to offset supine sleeping effects on motor skill acquisition

(Dudek-Shriber, L. et al. 2007) (Monson, RM. et al. 2003)

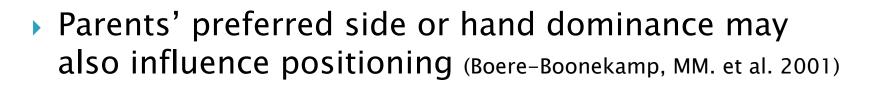


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### Feeding

- Feeding problems in infants with CMT and/or plagiocephaly include:
  - Asymmetrical jaw positioning (Wall, V. et al. 2006)
  - Preference for side of nursing
    or bottle feeding (Van Vlimmeren, L. et al. 2007)



Breast feeding from both sides may be preventative in lowering the risk of plagiocephaly (Losee, J. et al. 2007)



#### Additional positioning information: Fetters, L. et al. 2007; DeChalain, S. et al 2010



Parents should actively place infant in a variety of play positions during playtime, on changing tables in cribs or carriers:

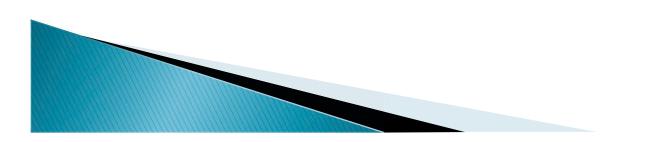




©2012 Children's Healthcare of Atlanta, Inc. All rights reserved 11. Determine Prognosis



- Benefit of parent education
- Classification of severity is important in communication with parents in order to discuss duration of treatment
- Provides parents with information



### Evidence based outcomes



- Prognosis of full resolution of CMT prior to 3 months is 100% and 75% if treatment is started after 3 months of age (Demirbilek, S. et al. 1997)
- Later onset of treatment (>3 months of age) the lower the chances of full resolution (Ohman, A. et al. 2010)
- The ability of the caregiver to implement a home program of active positioning and passive stretching correlates with a high level of resolution. (Ohman et al, 2009)

#### Overall Development Lobo, 2013 Tessmer, 2010



- Treat beyond body structure level
  - Infants with CMT and plagiocephaly may demonstrate delays in early motor development that will have an effect on perceptual motor skills and therefore cognition due to limited or asymmetrical exploration

 Lobo,M.; Harbourne S.; Dusing, S.; McCoy, S. Grounding Early Intervention: Physical Therapy Cannot Just Be About Motor Skills Anymore. *Physical Therapy.* 2013, 93 (1)

- 12. Physical Therapy Intervention for Infants with CMT
  - ▶ 5 components as the first choice intervention

1. Neck PROM







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#### 2. Neck and trunk active ROM





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### 3. Development of symmetrical movement (Rahlin, 2005; vanVlimmeren, 2008)

#### 4. Environmental adaptations





### 5. Parent/caregiver education



- Integrate into daily routine:
  - **Tummy time or prone play** (van Vlimmeren,2006; Ohman, 2009; Monson, 2003; Davis, 1998; Kennedy, 2009)
  - **Positioning and handling to encourage symmetry** (van Vlimmeren, 2006; Stellwagen, 2004; Ohman, 2011; Gray, 2009; van Vlimmeren, 2008)
  - Minimize time in bouncy seats and carrier as risk factor to plagiocephaly (Boere-Boonekamp, 2001; Stellwagen, 2004;Laughlin, 2011)
  - Alternate feeding to each side



(Losee, 2007)

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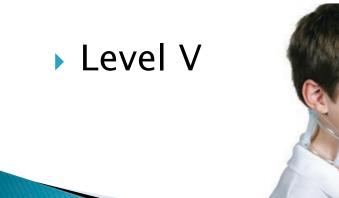
Duration and frequency of physical therapy

- Mildest forms: 2–3 months
- More severe forms: up to 5–6 months
- No dosage formulae
- CPG-CMT cannot define intensity treatment, except that stretching should be frequent throughout the day, every day

13. Provide supplemental intervention after AS 13 appraising appropriateness for the infant, to augment the first choice intervention

- Level II
- Level III
- Level IV

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14. Refer for consultation when outcomes are not fully achieved



- Considerations for refer if not progressing
  - If after 6 months there is a lack of progress
  - If a child begins after 1 year and presents with facial asymmetry and/or a 10-15 degree difference
  - If older than 7 months on initial exam and tight SCM mass

 Asymmetries of head, neck, and trunk not resolving after 4-6 weeks of initial intense treatment



#### Invasive procedures Botox or Surgery

- Two reasons
  - If after 6 months with conservative treatment lack of progress
  - After 1 year of age significant restriction and/or SCM mass





- Recommendation for surgery after period of conservative treatment between 6–12 months (vanVlimmeren, 2006; Burstein, 2004; Wei. 2001; Kozlov.2009)
  - More traditional approach (Lee, 2010; Kozlov, 2009; Lee, 2012)
  - Criteria used for timing of surgery (Cheng, 2001; Bursten, 2004; vanVlimmeren, 2006; Cheng, 2001)



# Physical Therapy Discharge and Follow up with Infants with CMT 15-16



Document outcomes and discharge infants from physical therapy when criteria are met (Christensen, 2013)



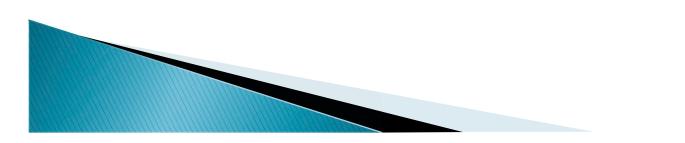
Provide a follow up screening of the infants 3–12 months post discharge (APTA Guide to physical therapy practice, 2001)



### Long term issues

 Not known if last 5-10 degrees resolves on their own or remains as a mild limitation

 Reevaluation of child entering elementary school if parent or teacher reports asymmetry, developmental delays, or preferential positioning (Wei, 2001)



### Lazardo Helmet Art







### Questions

