

CELEBRATING  
**THE TORCH**  
**WITHIN**

IRSF 25<sup>TH</sup> ANNUAL EDUCATION  
& AWARENESS CONFERENCE

Physical Therapy in girls  
with Rett Syndrome:

Fanning the *flame*



# Agenda

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- Motor Development and Needs
  - Patterns of development
  - Tone
  - Apraxia
- Physical Therapy Treatment
  - Positioning
  - Orthotics
  - School based services
  - Private services
- Pediatric Orthopedist
- Questions



# Gross Motor Skills Acquisition

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## Two major categories of milestones

- Fairly normal early milestones  $\Rightarrow$  regression  $\Rightarrow$  various rates and levels of recovery of skills
- Delayed milestones all along, sometimes so slowly that they don't seem to be gaining skills



# Gross Motor Milestones

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- Throw timelines and expectations out the window!!
- Missing milestone may not mean no gain
  - Can't roll over but may be able to maintain sitting with minimal support
  - Can't crawl but eventually walk
  - Can't stand from sitting but once standing take some steps with assistance or even walk independently



# Muscle Tone

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- Decreased tone (hypotonia)
- Increased tone (hypertonia)



# Muscle Tone: Decreased

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- ◉ Decreased tone (hypotonia)
  - Have to build more strength than others to be proficient at motor skills
  - May need orthotics for support of arches and/or control of ankle and knee
  - May need support to maintain good posture/alignment



# Muscle Tone: Increased

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- Increased tone (hypertonia)
  - May need orthotics to minimize contractures
  - May need support to maintain good posture/alignment



# Posture and positioning

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- ◉ With either high or low tone it is important to have good midline /symmetrical positioning
  - Firm sitting surface with adequate pressure relief
  - Lateral trunk and/or pelvic support
  - Possibly anterior trunk support and/or tilt option
  - Feet on the floor when possible (in classroom chair)



# Apraxia (Gross Motor)

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- Loss of the motor pattern
- Combat it with repeated practice of the task with as much independence as possible
- Find the least amount of help you can give so she can complete the transition herself...she needs to feel it in her own body.
- Decreased generalization of skills
- “Use it or lose it” principle applies



# Apraxia: Other considerations

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## Fear of Movement – can develop over time

- Can be due to increased apraxia ⇒ increased anxiety about moving/movement ⇒ decreased movement
- Onset may resemble “regression”

## What to do:

- Keep moving: actively, passively, and in combination
- Examples: transfers, therapy ball activities, swimming, horse back riding, bike trailer rides, rough housing

☺ Nice to find a family activity to meet this need!!!



# Orthotics: Ankle & Foot

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## ● Support in low tone

- Increased stability through support increases confidence to work on standing/walking skills
- Preventing pronation (by supporting arch)

## ● Support in high tone

- Blocking plantarflexion which interferes causing the girls walk on their toes, or become unstable in standing or stop walking altogether.



# Orthotics: Spine

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## Thoracic Lumbar Support Orthosis (TLSO)

- Orthopedist assist with need and type
- Consider abdominal cut-out for respiratory and GI function
- May increase level of assistance needed for transitions and walking



# School therapy

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- School PTs “hands may be tied” –  
”educationally relevant” treatment
- PT needs to:
  - Know how best to help with individual needs
  - Educate and train staff



# Outside/Private Therapy

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- Concerns of contractures or range of motion
  - Frequency: 1-4 sessions
  - Goal: updating home program, serial casting
- Period of improving skills, need for “tune-up”, or loss of gross motor skills
  - Frequency: 1-3 times/week for several weeks
  - Goal: maximize skills
- Acquiring equipment
  - 1-2 appointments
- Referrals? Treatment ideas?



# Orthopedics

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## Pediatric Orthopedist:

- Find one early on
  - Long term relationship
  - Establish baseline information
  - Resource for questions/concerns
- Topics to monitor:
  - Hip subluxation
  - Scoliosis
  - Other joint contractures



# Conclusion

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- Apraxia and muscle tone are forces to be reckoned with...keep them moving
- Find the least amount of assistance and support you can give....no matter what they are doing
- Balance school PT with private PT when needed
- A pediatric orthopedist is an important member of the team



# Questions???

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