Neuromuscular and Rehabilitation Care - tweens and teens

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Disclosures

• Susan Apkon is an investigator in clinical trials sponsored by Sarepta, PTC Therapeutics, Roche, and Biogen.
Tweens and Teens

• Responsiveness to change
  – World is bigger
  – Social issues more prominent
  – Separation is normal
  – Disease progresses
Neuromuscular Care

• Comprehensive care assessments 2x/year

• Continue steroids (consider starting*)
  – Monitor for steroid-related complications (cataracts, weight, growth, puberty, bone health)
  – Adjust dose for side effects

• Review novel treatments and clinical trials
Goals of Rehabilitation Management

• Maintain and maximize function

• Minimize contractures (tight joints) and spinal curve (scoliosis)

• Monitor function through standard assessment tools
  – Helps team to provide flexible recommendations
Rehabilitation Tools

- Therapy
- Orthoses (braces)
- Equipment
Therapy in the tweens and teens

- **PT** to guide exercise program, develop home stretching program, monitor equipment and bracing needs
- **OT** to focus on writing, adaptive skills, equipment needs and bracing needs
- **Speech** to focus on language and learning

**Training on new skills as function changes**
Orthoses

- **Night-time** resting splints (AFO’s)
- **Daytime** braces (AFO’s) when using wheelchair full-time
- **Hand splints** (WHO’s) when signs of wrist and finger tightness
Equipment

• Scooters and lightweight wheelchair for long distances
• Power wheelchair with supportive seating system

• Standing frames
• Bath/toilet equipment
• Lift equipment
Orthopedic management - Spine

- Spine
  - Assess clinically every 6 months
  - X-rays if curve observed or can’t see spine on exam
  - Referral to an orthopedic surgeon if curve present
  - Spine fusion for progressive curve
Orthopedic management - Fracture

• Ambulatory tween/teen
  – If goal to walk immediately surgery may be recommended

• Wheelchair dependent teen
  – Stabilize fracture with soft splint

Remember Fat Emboli syndrome