Physical Therapy

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Disclosures

- Program Manager ImagingDMD Studies
- Sub-Investigator ImagingDMD Studies
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- Instructor MedBridge Educational Courses

Pre Symptomatic Observations Commonly Reported

Stage 1 • Pre-Symptomatic
Stage 2 • Early Ambulatory
Stage 3 • Late Ambulatory-Transitional
Stage 4 • Early Non-ambulatory
Stage 5 • Late Non-ambulatory

Difficulty noted with:
- Climbing Stairs
- Getting up from the Floor - Partial Gowers Sign
- Jumping
- Running: slow, no flight phase
- Tin Walking
- Frequent Falling
- Weakness
- Leg Cramps
- Clumsiness
- Fatigue
- Large Calf Muscles
- Muscle Tightness Hamstrings/HTC
- Head lag on pull to sit - difficulty lifting head
- Decreased score on BSID III
- Fine Laparos
- Head lag or feet on bed
- Delayed Motor Skills
- Delayed Speech

Begin A Regular Routine

Make it Enjoyable.....Make it Fun!!!!

<table>
<thead>
<tr>
<th>Concentration Areas</th>
<th>Stretching</th>
</tr>
</thead>
<tbody>
<tr>
<td>Heel Cords</td>
<td>Incline Standing Board</td>
</tr>
<tr>
<td>Hamstrings</td>
<td>Long Sitting</td>
</tr>
<tr>
<td>Hip Muscles</td>
<td>Prone Lying</td>
</tr>
<tr>
<td>IT Band</td>
<td>Side Lying Stretch</td>
</tr>
<tr>
<td>Consider Initiation of Night Braces</td>
<td>Consider Behavior</td>
</tr>
</tbody>
</table>

Stretching

Start Early- Begin a Routine

- May help to maintain length of the muscle over time
- May improve comfort and positioning in bed
- Improve hygiene
- May improve fit of shoes
- May improve hand manipulation
- Improves Well Being
- Improves Circulation
Important areas of focus for Stretching

In The Beginning
- Stretching heel cords
- Stretching hamstring muscles
- Stretching hip flexors

STRETCHING IN THE BEGINNING

Hamstring stretch
Heel Cord Stretch
Hip Flexor stretch

Important Areas to Add for Stretching

Addition to stretching program
- Stretching forearm pronators
- Stretching elbow

ADDITIONAL STRETCHES

Stretching forearm pronators
Stretching elbow flexors

Stretching Resources for Parents

- PPMD Website
  Stretches for Duchenne Muscular Dystrophy 2019 View online
  http://www.parentprojectmd.org/site/PageServer?pagename=Care_resources_materials

- YouTube
  Stretches for Duchenne Muscular Dystrophy YouTube Video
  https://www.youtube.com/watch?v=6eHLt3KAOtg

- CINRG Website
  StretchOUT Stretch Instruction and Workout
  http://www.cinrgresearch.org/stretchvideo2/index.cfm

Pre-Symptomatic

Encourage Recreational Activities
**Early Ambulatory**
- Often just receiving diagnosis
- Elementary School
- Initiating Steroids
- Difficulty keeping up with peers
- Increased falling
- Occasional leg pain or cramping
- ROM (tightness may begin to develop or worsen)

**Common Measures**
**Clinic vs. Clinical Trial**
- Manual Muscle test
- Myometry
- Range of Motion
- Goniometry
- Postural and Gait assessment
- Timed Performance Tests
- North Star Ambulatory Assessment
- 6 minute walk test
- PUL
- Brooks Scale- UE
- Vignos Scale- LE

**Why Are Assessments So Important**
- Provide evidence for status and change in status
- Provide feedback for change in medication or treatment
- Demonstrate pattern of progression
- Predict need for intervention
  - Loss of ambulation: Equipment, home access, transportation, transfer teaching, support
  - Help explain status to parents and others

**Therapist’s Role**
Encourage, Instruct, Educate Families and Child, Be available to Consult
- Maximize Range of Motion and Gross Motor Skills
- Safety First
- Families should be instructed in
  - STRETCHING-Keep building a routine
  - Safe activities for play, recreation
- Maximize Balance and Coordination
- Maintain Overall Fitness
- Consult with School: Adaptations/Modifications
- DON’T OVER FATIGUE-Rest periods are “OK”

**How To Fit Everything In**
- Make stretching part of the daily routine
  - Brushing teeth
  - During homework position for success
  - Active assistive stretching- get child involved
- Equipment that might help improve/maintain ROM
  - Night splints
  - Standing wedge
  - Prone wedge

**Night Splints- Often Recommended**
*Consider Goals*
- Maintains prolonged stretch (6+hours/night)
  - Shown to be effective (Scott et al 1981, Hyde et al 2000)
- Night vs Day use
- Increased padding
- Shoes vs no shoes
Late Ambulatory-Transitional
A Time of Change

- Limited community mobility
- Increased risk of falls
- Increased fatigue
- Consider power wheel chair purchase
- Needs change: across life span
- Provider(s), location of services change with needs, and frequency
- Continual assessment of status and needs
- Goals are unique and challenging based on individual and family

Why Predicting Loss of Ambulation is Important

- The impact on families is huge and life changing
- Discussion: start early and repeat often
- Equipment often takes 6 months to receive
- Home modifications are costly and stressful
- Transportation becomes challenging
- Transfers are challenging
- School needs time to prepare (hooyer, classroom location, evacuation plan, etc.)

Fracture? Now what?

- Most often in the lower extremities
- Generally in boys older than 9 years
- Falls while ambulating
- Falls from wheelchair (seat belts!!)
- May result in loss of ambulation
- Boys need to avoid immobilization
- Families need to contact their specialists

Remobilization After Fracture

- Mat Exercise
- Aquatic Therapy
- Body Weight Supported TM
- Up and Free walker- may be an option
- Introduce weight bearing ASAP
- Work on Balance reactions

Early Non-Ambulatory

- Family education!!
- Encourage activity
  - Aquatic activities
    - Ergometers- active assist
  - Assistance for transfers
  - Equipment needs changing
- Increased tightness
- Disuse atrophy
- Increased weight gain
- Loss of functional independence
- Changes in community participation
- Initiation of BiPAP/ Cough Assist
- May increase risk of scoliosis

James et al, 2015; Subasi et al, 2016 Abstract MDA Clinical Conference
Consult “NEW” Care Guidelines: www.thelancet.com or www.parentprojectmd.org

Fractures
Late Non-Ambulatory

- May have increase c/o Pain
- Maximal Assistance
- Limited UE Function
- Respiratory Support
- Reliance on Technology
- Decreased Participation
- Decreased Employment Options
- May need to Employ Caregivers

Daily Routines Changing

- Transfers-more dependent
- Continue LE stretching
- Include UE stretching
- Sustained positioning
- ¼ - ¾ Prone lying if tolerated
- Side Lying
- Standing frames
- Elevating leg rests
- Reclining in WC

Assistive Technology

Exciting and Changing all the Time

- Blue tooth devices
- Siri/Dragon Speak
- Environmental control systems
- Google home & Amazon Echo
- Computers / tablets / smart phones
- Alternative keyboards/ touch pad screens
- Electronic pointing devices
- Voice assist (amplifiers)
- Glassouse
- TouchTapSwipe guide
  - (dmdpathfinders.org.uk)

MedTrade Expo

Largest Medical Equipment Tradeshow and Conference

Spring: Las Vegas February 2018-look at 2019 schedule for west coast dates
Fall: Atlanta October 2018

https://www.medtrade.com/

Historically

- Exercise recommendations have been based on rodent studies that induced injury
- Resultant recommendations were: exercise may cause damage- exercise with caution
- Current studies suggest
  - Exercise may be beneficial- BUT questions remain
  - Age?
  - How much?
  - What type?
Exercise

What do we know…..

- No exercise leads to muscle atrophy
- Important for bone health
- Important for self-esteem
- Too much exercise increases muscle breakdown
- Rhabdomyolysis
- Younger boys benefit from exercise more than older boys; however most of the research is with this group
- Boys with DMD are 40% less active than age matched peers (McDonald, 2000) ** supported by other studies

- Staying active is KEY
- Stretching may help to maintain ROM allowing activity and participation
- Age appropriate recreational activities as opposed to “resistive” strengthening regimes
- Concentric low load or isometric versus eccentric high load - stay submaximal - add power if needed/energy conservation
- Don’t overdo!! Build in Rest Periods
- Self modulation
- Structured breaks
- Fatigue is REAL, Differences in endurance
- Incorporate balance and coordination skills

Assisted bicycle training delays functional deterioration in boys with Duchenne muscular dystrophy: the randomized controlled trial “no use is disuse”.

Jansen M, van Alfen N, Geurts AC, de Groot IJ

- Arm and Leg Ergometer Ex-n-Flex (active assist)
  - 24 boys age 8-12 years (amb and non-amb)
  - Training at 50% max, 40 minutes, 3 day/week
  - 24 weeks
- Assisted bicycle training
  - Delays functional deterioration in boys with DMD
  - Outcomes remained stable (MFM and Assisted 6min cycling test)
  - No serious adverse events
  - Safe and feasible
  - May decline the deterioration due to disuse

Different types of upper extremity exercise training in Duchenne muscular dystrophy: effects on functional performance, strength, endurance, and ambulation.

Kanekalakshmi L, Kasumuran A, Yilmaz OT, Topaloglu H

- Subjects = 24 boys ages 8-12 y/o, ambulatory
- Study group n=12 * assistive UE ex/PT-Arm Ergometer
  - 40 minutes per session, 3x/week x 8 weeks
  - Positive effects on subjects’ muscular endurance, performance of ADL’s arm function, ambulation status - NO significant change in muscular strength
- Control group n=12 *strengthening ROM ex/Family
  - 40 minutes per session, 5x/week x 8 weeks
  - Improved grip strength and endurance only
  - Improved NSAA score
- Summary - Both groups improved to varying levels

Pilot Study for Mild to Moderate-Intensity Resistance Exercise in Boys with Duchenne Muscular Dystrophy

DJ Lott, KD Cooke, HJ Park, BM Black, SC Forbes, BJ Byrne, GA Walter, K Vandenborne

- Subjects: 8 ambulatory boys w/DMD (8.3 ± 0.7yr)
- Safety Measures: 48 hr before/after
  - T2 weighted MRI
  - Pain assessment
  - Clinic Exam & CK levels
- Protocol: 4 exercises-isometric maximal voluntary contraction (MVC)
  - Quads and Hams at 2 different angles
  - Isometric exercise-Mild level (30%MVC) n=4
  - Isometric exercise-Moderate level (50%MVC) n=4
- Example of protocol
  - Exercise Hamstrings - 30 and 60 degrees
  - Exercise Quadriceps - 30 and 60 degrees
- Preliminary Results indicate that exercise is feasible and safe and may be beneficial

Resources in Alabama

- Therapy services at Children’s and Beyond
- Community resources
- Education support
- Equipment resources
- Recreation
- Participation

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Therapy Services at Children’s and Beyond

- **Outpatient COA PT & OT:** 205-638-9645; 205-638-6289
- **Outpatient PT:** Night splinting; Equipment referrals – wheelchairs, patient lifts, stands, bathing, stretching, positioning; Home modifications; School consultation; Plan for college mobility
- **Outpatient OT:** Hand splinting; Stretching; ADL’s; Adaptive equipment; Mobile Arm Supports; Carring control; Wheelchair adaptations; Head control; joystick adaptations; Voice activated system; Assistive technology; Home modifications recommendations; School strategies; Sleeping positions; Plan for college needs
- **Hippotherapy:** Special Equestrians (205) 987-WHOA-One on One therapy using the horse
- **Aquatic therapy:** Huntsville Hospital for Women and Children – 256-265-7652; Champion Sports Medicine - 205-871-8882

Community Resources

- **Children’s Rehabilitation Services:** Assist with wheelchair costs; Back up manual wheelchair; Home assessment and modifications; Transfer equipment; Bathing equipment; Service coordination (Muscle Shoals, Huntsville, Gadsden, Anniston, Birmingham/Homewood, Tuscaloosa, Selma, Montgomery, Opp, Jackson, Andalusia, Dothan) - www.rehab.alabama.gov
- **ADRS at Lakeshore:** Adaptive Driving Training; Assistive Technology; Employability Development; Vocational training - Phone: (205) 870-5999
- **Teen Transition Clinic:** To assist adolescents and young adults in their planning, for transition to adult life are eligible to participate in the clinic; www.rehab.alabama.gov

Equipment

- **Wheelchair vendors:** Numotion (205-833-0284); National Seating and Mobility (205-621-7332); Alabama Wheelchair (205-322-3250) (especially short term rentals)
- **Orthotics:** Biotech Limb and Brace (205-324-7897); Hanger Orthotics (Birmingham, Montgomery, Tuscaloosa, Mobile; Talladega)
  - Birmingham Limb and Brace; Precision Medical Solutions: Montgomery - 334-260-3767; Auburn - 334-826-0078

Education Support

- **ADAP services:** ADAP provides legal services to Alabamians with disabilities to protect, promote and expand their rights. adap@ua.edu;
- **Bullying:** Children’s Mental Health; Early Childhood; Foster care; Juvenile Justice; Special education
- **Children’s of Alabama PT & OT – 205-638-9646 - Consult to schools**

Recreation

- **Lakeshore** (205-313-7400) Lakeshore.org; Activities separated by age - Swim classes; Active children exercises (ACES); Mini Movers; Fish out of Water; Fresh; Archery; Track and Field
- **Local YMCA’s Swimming!!!!**
  - Adairsville, Americus, Athens, Bessemer, Birmingham, Verbena, Pelham, Trussville, Mountain Brook, Brewster, Chilton County, Daphne, Enterprise, Florence, Fultondale, Odenville
More Recreation

Therapeutic Horse Back Riding: Special Equestrians, Birmingham - (205) 987-9462; www.specialquest.org; The Red Barn, Leeds (theredbarn.org) (205) 699-8204; Storybook Farm, Opelika - (334) 444-5966; www.hopeonhorseback.org; Therapeutic Riding of Tuscaloosa, 712 355-8962 or 205 752-7691; www.trotusa.org; Happy Trails Therapeutic Riding Center, New Market - happytrailstrc.org

More Recreation

• Miracle League Baseball: North Alabama (mhuntsville.com); Coastal Alabama (miracleleaguecoastalalabama.com); Tuscaloosa (miracleleagueoftuscaloosa.com); Montgomery (montgomerymiracleleague.com); East Alabama (miraclefield.org); Dothan; Over the Mountain; Gardendale

• Miracle League Soccer – available in some locations

Participation

• Lakeshore: 205-313-7400- include siblings and friends; Super Saturdays – fun; Camp Strike, JWAS; Adventure and Inclusion summer camps; Movie nights

• Lakeshore sports teams: Power soccer; Swim team; Bocce ball; Wheelchair basketball; Wheelchair rugby

• State campgrounds: 1-800-ALA-PARK (252-7275); www.alapark.com

Participation continued

• Camp ASCCA- Jackson’s Gap, AL - (256) 825-9226 – summer and year long weekend camps – one week designated for DMD – staff well trained - horseback riding, swimming, canoeing, fishing, arts and crafts, accessible waterslide, zip-line, water tubing, archery and rifle range, mini-golf course, paved nature trails, splash pad…..

School Environment

Things to Consider

• IEP and/or 504 Plans

• Accessibility issues

• PE/ Field trip participation

• Safety Plans

• Equipment for transfers

• Toileting equipment
Common Campus Modifications

- Extra time to get to class
  - Classes close together if possible
- Individualized PE modifications
  - With extended breaks as needed
  - Adaptive sports (involve the whole class for socialization)
- Use of accessible bathroom
- Key for elevator (for those still ambulating)
- Staff trained in transfers (using a lift)
- Assistance for lunch set up
- Safety evacuation plan

Common Classroom Modifications

- Copies of PowerPoints or notes
- Extra set of books for home
- Use of laptop/tablet or scribe
- Modified homework to limit fatigue
- Extra time for standardized or timed tests
- Oral tests if writing difficult
- One-on-one aide
- Individualized and preferential seating or desk

Transition to Higher Education

Resources
- State Vocational Rehabilitation Department
- STAR program
- Scholarships & Financial Aids
  - https://www.mda.org/young-adults/resources
- College or University Office of Student Disability Services
- Center for Independent Living (dependent on location)

What is Vocational Rehabilitation?

http://www.rehabworks.org

What is it?
Federal program designed to:
- Enhance independence of people with disabilities by helping them find and maintain employment

Services
- Can vary at each location
- Ranges from:
  - Career Counseling
  - Job Training & Placement
  - Supported Employment
  - Assistive Tech training & support
  - Medical & Psychological Assessment
- STAR Program
  - Ages 15-21 for students

Thank you!

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