Charcot Marie Tooth Association

Webinar 12/19/13

James Nussbaum, PT, PhD, SCS, EMT
Clinical and Research Director
www.prohealthptot.com
Skilled Physical Therapy and Exercise to Improve Function and QOL in CMT

“EVERY patient with CMT should be evaluated by a skilled PT and OT”

ProHealth & Fitness, James Nussbaum, PhD, MSPT, SCS, CSCS, EMT
Skilled Physical Therapy and Exercise to Improve Function and Quality of Life in CMT

The CMTA is proud to announce an upcoming webinar featuring CMTA Advisory Board Member, James Nussbaum. The title of this webinar is, Skilled Physical Therapy and Exercise to Improve Function and Quality of Life in CMT. James will discuss some of the more common therapeutic benefits in people with a diagnosis of CMT. He will discuss cardiovascular exercise, resistance, balance, and functional exercise guidelines, and some of the literature behind these recommendations. The discussion will include tips and ideas for young children to older adults and everyone in between. Specific individualized exercise and therapeutic recommendations can only be made individually.
Skilled Physical Therapy and Exercise to Improve Function and QOL in CMT

Disclaimer:
○ JN’s opinion, there are many who disagree
○ All exercise and activities should be cleared by an expert
○ Consult YOUR doctor PRIOR to engaging in any new activity
○ You may ask your doctor to speak with another expert

There is no sponsor, and I have no interest(s) to disclose

“EVERY patient with CMT should be evaluated by a skilled PT and OT”
Skilled Physical Therapy and Exercise to Improve Function and QOL in CMT

- BACKGROUND
- DEFINITION(S)
- IMPAIRMENTS
- LITERATURE
- HOW TO IMPROVE FUNCTION
- SUMMARY, Q & A
BACKGROUND

James Nussbaum, PT, PhD, SCS, EMT

American Red Cross – Instructor
NYS Department of Health – Emergency Med Technician
NYS Department of Health - Fall Prevention Task Force
Johnson & Johnson Health Care Systems - Health & Fitness Specialist
Touro College of Health Science - MS PT
National Strength & Conditioning Assoc. - CSCS, Strength Specialist
NYC Department of Education - Senior Physical Therapist
Cambridge State University - PhD Pathokinesiology
American Physical Therapy Assoc. - Sports Certification Specialist
Andrews University, Touro College, LIU - Clinical Instructor
Touro College PT Program – Advisory Board
Charcot Marie Tooth Association – Advisory Board
TRIARQ – Medical Advisory Board - Research Co-Dir
International and National Presenter - PT and Exercise
The primary goal of healthcare should be to improve quality of life (QOL)

What impacts QOL?
- Independence
- Mobility
- Comfort
- Control

Each specialist plays her/his part in working with their patient to improve QOL
GOAL:

- Functional independence
- Activity tolerance
- Mobility
- Activities of daily living
- Recreational activities
- Enable patients to have choices

Who are the experts in testing and improving function?

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Skilled Physical Therapy and Exercise to Improve Function and QOL in CMT
EXERCISE:
Physical exercise is any bodily activity that enhances or maintains physical fitness and overall health and wellness. It is performed for various reasons including strengthening muscles and the cardiovascular system, honing athletic skills, weight loss or maintenance, as well as for the purpose of enjoyment.

PHYSICAL THERAPY:
Physical therapy or physiotherapy is a health care profession primarily concerned with the remediation of impairments and disabilities and the promotion of mobility, functional ability, quality of life and movement potential through examination, evaluation, diagnosis and physical intervention.

*Wikipedia
DEFINITION

FALL

“An event, which results in a person coming to rest inadvertently on the ground or other lower level”

World Health Organization
IMPAIRMENTS

- PAIN
- FATIGUE
- WEAKNESS
- MUSCLE LOSS
- SENSORY LOSS
- IMBALANCE / FALLS
- JOINT DEFORMITIES
- AUTONOMIC DYSFUNCTION

- CO-MORBIDITIES
LITERATURE REVIEW

PUBMED  “PD and Exercise” = 957 citations
          “MS and exercise” = 853 citations

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LITERATURE REVIEW

PUBMED  “CMT and Exercise ” = 40-53 citations
IS EXERCISE GOOD or IS EXERCISE BAD?
(in patients with a chronic progressive neurological disorder like CMT)
LITERATURE REVIEW

CONSENSUS?

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LITERATURE REVIEW

Michael Shy
Steven Scherer

Robert Chetlin
Sharon DeMuth
L. El Mhandi
Fransisco Fernandez - CMTA
W.M. Fowler
R. Ted Abresch
Gita Ramdharry***

MANY MORE

PUBMED  “CMT and Exercise ” = 40 citations
“Strength Training and CMT = 10!!!

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LITERATURE REVIEW

POSSIBLE PITFALL

“OVERWORK WEAKNESS”

- CHEMICAL
- STRUCTURAL
- ELECTRICAL

DOMINANT HAND VERSUS NON DOMINANT

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Verifying the hypothesis of overwork weakness in Charcot Marie Tooth
Annemieke Videler J Rehab Medicine 2010

Overwork weakness in Charcot-Marie-Tooth disease

Importance of Overwork Weakness
Fowler WM. Muscle Nerve 1984

Dystrophinopathy in two young boys with exercise-induced cramps and myoglobinuria
C. Minetti et al. European J of Ped 1993

Over-Weakness in Fascioscapulohumeral Muscular Dystrophy
Johnson and Braddock Arch Phys Med and Rehab 1971
OVERWORK WEAKNESS

Overwork weakness in Charcot-Marie-Tooth disease.

Importance of overwork weakness.
Fowler WM Jr. Muscle Nerve 1984

Overwork weakness with evidence of muscle damage in a patient with residual paralysis from polio.
Peach FE. Arch Phys Med Rehabil 1990

Effects of excessive use of remaining muscle fibers in prior polio and LV lesion.
Borg K. Et al. Muscle Nerve 1988
The hypothesis of overwork weakness in Charcot-Marie-Tooth: a critical evaluation. 

It has been reported that the non-dominant hand of patients with Charcot-Marie-Tooth disease is stronger than the dominant hand as a result of overwork weakness. The objective of this study was to determine if this hypothesis could be verified in our population. Twenty-eight patients with CMT in the Netherlands.

**CONCLUSION:**
In our population, the dominant hand of patients with Charcot-Marie-Tooth disease type I and II was equally strong as the non-dominant hand, suggesting that there is no presence of overwork weakness in the dominant hand in our group of patients. This implies that patients with Charcot-Marie-Tooth disease do not have to limit the use of their hands in daily life in order to prevent muscle strength loss.
LITERATURE REVIEW

AUTONOMIC DYSFUNCTION

EXERCISE TRAINING IMPROVES AUTONOMIC PROFILES IN PATIENTS WITH CHARCOT-MARIE-TOOTH DISEASE

EL MHANDI et al. MUSCLE & NERVE 2011

8 patients - interval training improves hear rate variability (autonomic function) by increasing parasympathetic activity
Patients respond to resistance training with muscle fiber adaptations, and improvements in strength and function.
LITERATURE REVIEW

Activities of Daily Living (ADL)

Resistance Training Effectiveness in Patients With Charcot-Marie-Tooth Disease: Recommendations for Exercise Prescription

12 weeks home based resistance training program. Conclusions: Resistance training improved strength and ADLs equally in men and women.
Activities of Daily Living (ADL)

Resistance Training Effectiveness in Patients With Charcot-Marie-Tooth Disease: Recommendations for Exercise Prescription

12 weeks home based resistance training program.

Conclusions: Resistance training improved strength and ADLs equally in men and women.
Outcome Measures

Outcome Measures and Rehabilitation Treatment in Patients Affected by Charcot-Marie-Tooth Neuropathy A Pilot Study

Eight (L) patient participated in twice weekly activities for 8 weeks. “No dropouts or worsening in any of the different outcome measures were observed after TreSPE. The ankle angle and the time to walk 6m were the only measures that significantly improved after treatment.”
LITERATURE REVIEW

ROBUST STUDIES?

UNEQUIVOCAL EVIDENCE?

CLEAR PROGRAMATIC PROTOCOLS?

WHITE PAPERS AND RECOMMENDATIONS?

BUT DOES THAT MEAN THAT>>>?

PEOPLE WITH CMT SHOULDN'T EXERCISE?
WHAT TO DO IN THE ABSENCE OF CLARITY

FIND A (CMT) CENTER OF EXCELLENCE

CONSULT WITH EXPERTS

BE PROACTIVE

SUPPORT THE ASSOCIATION

“ALWAYS AND NEVER”
shouldn’t be used too often

FIND SKILLED PTs and OTS, get evaluated

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EVERYONE SHOULD EXERCISE

EVERYONE WITH CMT SHOULD EXERCISE

EXERCISE IS GOOD FOR EVERYONE
- AT THE RIGHT TIME
- IN THE RIGHT DOSE
- USING THE RIGHT MODE
- APPROPRIATE INTENSITY
- PROPER REST PERIOD(S)

*UNDER SKILLED GUIDANCE/SUPERVISION*
HOW TO MAKE FUNCTIONAL CHANGE?

USE THE EXPERTS IN FUNCTION

PHYSICAL THERAPISTS

OCCUPATIONAL THERAPISTS

TEAM WORK

PATIENT, FAMILY, HHA, CSW, NEURO, PM&R, ORTHO, P&O, RHEUM, CARDIO, PULM, PSYCH, etc.
I WANT TO GIVE THIS A TRY, NOW WHAT?

FIND A SKILLED PT and OT and get an EVALUATION

SPEAK TO YOUR DOCTOR

INSURANCE....................$$$$$$$

WHAT IS COVERED?

○ TODAY VERSUS NEXT WEEK, TWO WEEKS...
HOW TO MAKE FUNCTIONAL CHANGE?

EVALUATION: ID DEFICITS

LISTEN TO THE PATIENT
SKILLFULLY LOOK AT FUNCTION
OUTCOME MEASURES
Objective, valid, and reliable

INTERVENTION(S)
LISTEN TO THE PATIENT
SKILLFULLY LOOK AT FUNCTION
OUTCOME MEASURES
Objective, valid, and reliable
Occupational Therapy Intervention

• **ADL training - Basic and Instrumental**
  - Dressing, Grooming, Feeding, and Writing

• **Fine motor control**
  - Intrinsic muscle strength, dexterity, coordination

• **Trunk, Shoulder, Elbow, and Hand function**
  - Improve motion with mobilization and PNF
  - Decrease pain with modalities
  - Strengthen with therapeutic exercise/activities
PROGRAM DESIGN

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SKILLED PHYSICAL THERAPY INTERVENTION

**EVALUATION**
- Objective, valid, reliable outcome measures

**PLAN OF CARE**
- Treatment specifics, contraindications

**THERAPEUTIC ACTIVITIES**
- Transfer training, AD fitting and utilization

**ORTHOTIC MANAGEMENT**
- Recommendation, fitting, functional usage

**NEUROMUSCULAR RE-EDUCATION**
- Static and dynamic balance activities, posture

**MANUAL TECHNIQUES**
- Soft tissue work, joint mobilization, pain Rx

**THERAPEUTIC MODALITIES**
- E-stim, US, cold laser, NIRPT, thermal, more?

**THERAPEUTIC EXERCISE**
- Program design principles, HEP

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EVALUATION

SUBJECTIVE
OBJECTIVE
ASSESSMENT
PLAN

OUTCOME MEASURES

CLINICAL TESTS
FUNCTIONAL TESTS
QUESTIONNAIRES

REPEATABLE!
FALL/BALANCE (RELATED) ASSESSMENTS

- TUG
- Gait Speed
- FAB
- BERG
- DGI
- 4 Square
- mCTSIB
- STS (5, 10, 30, 60)
- ABC
- FES
- SAFE
- STEADI
Effective Exercise for the Prevention of Falls: A Systematic Review and Meta-Analysis

Catherine Sherrington, et al

Journal of the American Geriatric Society  2008
THERAPEUTIC EXERCISE

Program Design
Principles:
- Mode, Repetitions, Sets, Intensity, Rest, Frequency, Volume

Energy system

- Intensity
  - HR
  - %RM
  - RPE

- Work: Rest
  - Rest
  - Duration

Assess ↔ Modify
PHYSICAL THERAPY

DIRECT APPROACH

INDIRECT APPROACH
LOWER EXTREMITY

EXERCISE CHOICES:

SIMPLE ↔ COMPLEX?

COMPLEX ↔ SIMPLE?

OKC versus CKC?

MODE, VOLUME, INTENSITY, FREQUENCY, REST, ……?

IN THE PRESENCE OF PATHOLOGY?
EXERCISE CHOICES: Do’s and Don'ts
Who is this NOT appropriate for and why?
THE WATER IS THE BEST PLACE TO EXERCISE, SAID WHO?
MOVEMENT vs. MUSCLES

SYNERGISTIC MUSCLES
AGONIST vs. ANTAGONIST
OCK vs. CKC
CONCENTRIC or ECCENTRIC
STABILITY vs. MOBILITY
LENGTH TENSION RELATIONSHIPS
LOWER EXTREMITY

EXERCISE CHOICES:

SIMPLE ⇔ COMPLEX?

COMPLEX ⇔ SIMPLE?

OKC versus CKC?

MODE, VOLUME, INTENSITY, FREQUENCY, REST, ......?
BIODEX BALANCE SYSTEM
Where is the ROM coming from?

What are the passive restraints?

What are the active restraints?

Flexibility vs. ROM

What am I shooting for?
Lower Extremity

PROPRIOCEPTION
Physical and Occupational Therapy

MACHINES or NO MACHINES?

BIODEX UE & LE
BIODEX BALANCE
KEISER TRAINER

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JUMP SQUAT

RISK: BENEFIT RATIO
Evaluation
Identification of deficits
STG and LGT

Plan of Care
Summary of evaluation
Recommendations
Precautions/Contraindications

Implementation
Skilled PT and OT Services

Progress Report
Functional Progress
WE CAN WORK TOGETHER TO MAKE A DIFFERENCE

CALL A LOCAL THERAPIST TODAY

COMMUNICATION IS KEY
Through skilled therapy:
Falls can be prevented
ADLs can be made more independent
Mobility can increase
Community access can be enjoyed, and
Quality of life can be improved

IT STARTS WITH AN EVALUATION
Health Care = Quality of Life

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CMT Program
CMTA
ProHealth & Fitness PT OT

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THANK YOU

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Figure 3.2  (a) A motion 1, (b) A motion 2, and (c) A motion 3.
FIRE HYDRANT
What do we do and when do we do it?
Risk benefit ratio
Lower Extremity

OKC, is it really?
FALLS:

- U.S. > $30 billion on falls
- 1 of 3 adults >65 will fall
- 1 of 2 adults >80 will fall
- AAOS: >90% of > 352,000 annual hip Fx in the U.S. are the result of a fall.
- Only 25% pts s/p hip Fx - full recovery
- >20% mortality < 1 year post hip Fx
- ~25% institutionalized rest of their lives s/p Fx

Center for Disease Control - US
NEW STATE TASK FORCE ON FALL PREVENTION

Among adults 65 and older who are hospitalized due to a fall:

- 60% end up in a nursing home or rehab center
- 11% suffer a traumatic brain injury
- 27% experience a hip fracture
Can we prevent Falls?

Exercise can reduce fall rates
Balance training
~ 50 hours of intervention over 6 months

Numerous programs work!

Sherrington et al, JAGS 2008

WHO PAYS FOR IT?
Fall Prevention Programs

INDIVIDUALIZED

GROUP CLASSES
FALL PREVENTION PROGRAMS

INDIVIDUALIZED:
- SPECIFIC DEFICITS
- UNIQUE LIMITATIONS
- LTG – IMPORTANT TO PATIENT

GROUP:
- LEAST COMMON DENOMINATOR
- LIMITED BY SAFETY CONCERNS
HOW DOES SKILLED PHYSICAL THERAPY PREVENT FALLS?

- STRENGTH TRAINING
  - Program Design
    - Mode, Volume, Intensity, Frequency
    - Rest Periods, Fiber Types, ........
    - 3 X 10?
  - Plan of Care
HOW DOES SKILLED PHYSICAL THERAPY PREVENT FALLS?

- Perturbation Training
- Multi Directional Lunging
- Executive Function Work
- Reflex and Power Training
- Sensory Integration
HOW DOES SKILLED PHYSICAL THERAPY PREVENT FALLS?

Turn the purposeful, habitual

- REPETITION
- ENVIRONMENT
- BUILD UPON SUCCESS
- CREATE SKILLS and HABITS
- INSTILL APPROPRIATE CONFIDENCE