VCP DISEASE AND
EXERCISE

Improving what you have and slowing the disease

James Wymer MD, PhD
Lisa Warren, MHS, OTR/L
Alison Kraus PT, DPT, NCS

Board Certified Neurologic Physical Therapist

Norman Fixel Institute for Neurological Diseases
3009 SW Williston Rd, Gainesville, FL, 32608
VCP Disease and Exercise

- What we know about care and exercise from other diseases
- Occupational therapy to improve and maintain function
- Physical therapy and exercise
Reactive to Proactive
Fighting VCP

Speech and Language Pathologist

Basic Scientist

MDs, RNs, NPs, PAs, & DOs

Occupational Therapist

Psychologist (cognitive therapist)

Physical Therapist

Clinical Scientist

Community Support

Social Worker
THE OPPORTUNITY...

Can we be doing something to improve and/or maintain strength and function to fight this?
Physiologic Reserve

Age

Lingual Pressure (kPa)

Physiologic Reserve
Law of Diminishing Reserve: 

Aging, Prolonged Illness, ND Disease REDUCES PHYSIOLOGIC RESERVE

![Graph showing the law of diminishing reserve with axes for Time and Lingular Pressure (kPa). The graph illustrates how physiologic reserve is reduced over time, leading to a deficit.](attachment:image.png)
Training to Increase Physiologic Reserve:
Expiratory Muscle Strength Training
Maximum Expiratory Pressure

- MEP (cmH₂O)
- Treatment Session
- Expected MEP
Individual responses
Inclusion Body Myositis

- 59% increase in MEP
- 58% increase in MIP
- 28% increase in Peak Cough Flow
- 0.38L increase in FVC
SO WHAT CAN WE DO??
Occupational Therapy for VCP

- **Goal is to enable people to live life to its fullest through adaptation and/or compensatory strategies**

  - *Focus is on adapting the environment or the task*
Can I continue to do my daily tasks?

- *Training on seated activities when standing is too difficult*
  - Brushing teeth, shaving, showering, dressing, cooking, etc...

- Sitting to complete daily tasks, conserves your energy
Daily tasks

- Use of mobile arm supports to brush teeth, shave, put on make-up and to eat
Daily tasks with use of adaptive devices

- Techniques and strategies for dressing and reaching when shoulder, trunk and hip muscles are weak
  - Use of body mechanics and adaptive equipment
Adaptive equipment
Positioning for support and function
Home modification recommendations
PHYSICAL THERAPY FOR VCP
Why Physical Therapy for VCP?

- Myopathy affects 90% of patients with IBMPFD
  - Muscle atrophy is usually progressive, and most people will eventually need to use a wheelchair and other mechanical aids for mobility
  - Usually affects proximal muscles (hips, shoulders, trunk) prior to affecting distal muscles (calves, ankles, feet, hands, wrist)
  - Can affect cardiac and respiratory muscles

https://www.curevcp.org/
Can Physical Therapy Help?

- Maintaining mobility can help lessen, delay, or manage the symptoms from VCP

  OR

- Coordinating care for appropriate equipment:
  - Rollator Walker
  - Cane
  - Manual Wheelchair
  - Powered Wheelchair
Can we exercise these patients safely?

- Early-stage patients show *skeletal muscle mass* similar to that of healthy individuals BUT a *reduced peak oxygen uptake*
  - *Most likely associated with deconditioning and reduction in habitual activities*

- Lack of physical activity results in deconditioning and compounded weakness from disease

- Contractures and joint tightness caused by inactivity may result in pain and reduced capacity to carry out ADLs
What Kind of Exercise?

Resistance vs Aerobic vs Flexibility

**Stretching:** increase tendon flexibility to improve joint ROM and function to enhance muscular performance

**Resistance Exercise:** increase muscle strength and power; improve EFFECTIVE recruitment of motor units (improve specific brain to muscle activation)

**Aerobic Exercise:** increase in oxidative potential of skeletal muscle, can lead to increase in mitochondrial volume, improve exercise capacity, reduce psychological stress, reduce diseases including heart disease, diabetes and cancer
Stretching is **SAFE**

- The more flexible your muscles, the easier it will be to move them during functional activities, even when there is weakness.
Stretching is **SAFE**
Resistance vs Endurance vs Stretching

In other Neuromuscular Disorders:

Exercises performed 3x/week

- **Resistance** using cuff weights and machines (40-70% of 1RM for 2 sets of 8)
  - Shoulder Flexion, Elbow Flexion, Elbow Extension, Grip, Hip Flexion, Knee Extension, Knee Flexion

- **Endurance** using mini cycle for UE and LE (40-70% of Target HR or 13-15 or “somewhat hard to hard” on the Borg)
  - 10 minutes of UE and 10 minutes of LE

- **Stretching** done passively with an ‘exercise buddy’ (4x30 seconds of each)
  - Shoulder flexion, Triceps, Hand/Wrist, Hamstrings, Gastroc, Quadriceps
Resistance vs Endurance vs Stretching

Outcome:
- All exercises well tolerated (>50% compliance) at 12 and 24 weeks and safe
  - *Endurance exercise was less tolerated than stretching and resistance*
- No worsening in fatigue, pain or cramps as well as no worsening in disease progression

Trend towards **fewer falls** in endurance and resistance exercise groups compared with Stretching group
Resistance Training

- resistance exercises 3 times a week along with daily stretching
- Vs. daily stretching alone
- The resistance group performed moderate-intensity upper and lower extremity resistance exercises that were individualized for each subject.

Resistance

- statistically significant improvements in functional scores, better quality of life, smaller decline in leg strength, and no negative outcomes
Aerobic Exercise

Only 6 patients: underwent BWSTT for 30 min, broken up in 5-min segments, 3 times per week for an 8-wk period.

Improvements noted in function and fatigue scores as well as gait speed, distance, and stride length.
Systematic Review of Exercise with Neuromuscular Disease

Chief Conclusion:

- **Resistance Training** showed: Improvements in **functional scores** but not in muscle strength or quality of life

- **Aerobic Exercise** showed: Moderate-Intensity physical exercise program had a short-lived positive effect on disability
  - Improved **functional scoring** and disease symptoms

- **Stretching**: An aggressive/daily program for stretching and ROM exercises is widely accepted as common prescription for disease management
An Idea to Consider with Physical Therapy Visits:

- Space Visits of Skilled Physical Therapy out over time to allow patient to have therapy the whole year to address changing needs and adapt Home Program

- Maintenance Visits with a Progressive Neurological Condition
  
  Ex: 2 visits of Physical Therapy each Month for 12 months instead of “burst therapy”