

# Using Exercise and Other Physical Therapy Interventions to Optimize Functional Mobility

Joseph Shrader, *PT, CPed*



The 2018 **Kennedy's Disease** Conference  
ASSOCIATION



# Disclaimer

The views expressed in these materials do not necessarily reflect the official policies of the U.S. Department of Health and Human Services, the NIH or its components; nor does the inclusion of trade names/logos/trademarks/or references to outside entities constitute or imply an endorsement by any Federal entity.

General exercises discussed and demonstrated in this presentation should not be taken as individual exercise advice. Exercise prescriptions will vary widely among individuals based on many health factors. We recommend consulting your medical professionals (i.e. physician, physical therapist, etc.) to evaluate your physical health, determine the most appropriate exercise prescription, and monitor the safety of your program.



# Physical Therapy and Kennedy's Disease

- I. Importance of Exercise and Physical Activity
- II. Exercise Research in Kennedy's Disease
- III. Considerations, Precautions, and Adaptive strategies
- IV. Foot and Ankle Considerations
- V. Exercise Recommendations for Varying Functional Levels
- VI. Question & Answer Session

# Importance of Exercise and Physical Activity

# Physical Activity vs Exercise

## Terminology

- **Physical activity:** any motion of the body that results from skeletal muscle contraction and energy expenditure
- **Exercise:** any physical activity used to develop or maintain fitness, or a skill.
- **Sedentary:** those using < 10% of their daily caloric expenditure in the performance of moderate or high-intensity activities

# 2018 Physical Activity Guidelines

- 10 year literature review abundantly demonstrates that physical activity is a best buy for public health.
- Detailed summary of both disease prevention and health promotion benefits.
- Major findings: Improves deep sleep and executive functioning, decreases depressive and anxiety symptoms, improves physical function and quality of life and decreases fall risk and fall related injuries and contributes to older adults ability to remain independent.
- Recommend 150-300 minutes of moderate activity/week
- Recommend combining Aerobic and Strength training

# Activity in Kennedy's Disease - Preliminary

- Average daily steps for men with KD = 3,655
- Compared with NHANES age 60-64 men = 4,455
- Average hours of activity over 10 days
  - Sedentary = 20 hrs
  - Light = 3 hrs
  - Moderate = 1 hr
  - Vigorous = 0 hrs

# Activity in Kennedy's Disease

- Subjects who walked more had better health related quality of life and TUG times.
- Older subjects expended less energy throughout the day.
- Independent of age, those with worse TUG and AMAT values spent less energy throughout the day.

# Why should we Exercise?



- Improve Physical Fitness
  - Aerobic
  - Balance
  - Body weight
  - Energy-Expenditure and Fatigability
  - Flexibility
  - Functional Activity
  - Strength
- Reduce risk of adverse health outcomes
- Optimize physical function
- Enhancing Quality of Life
- It Can be enjoyable

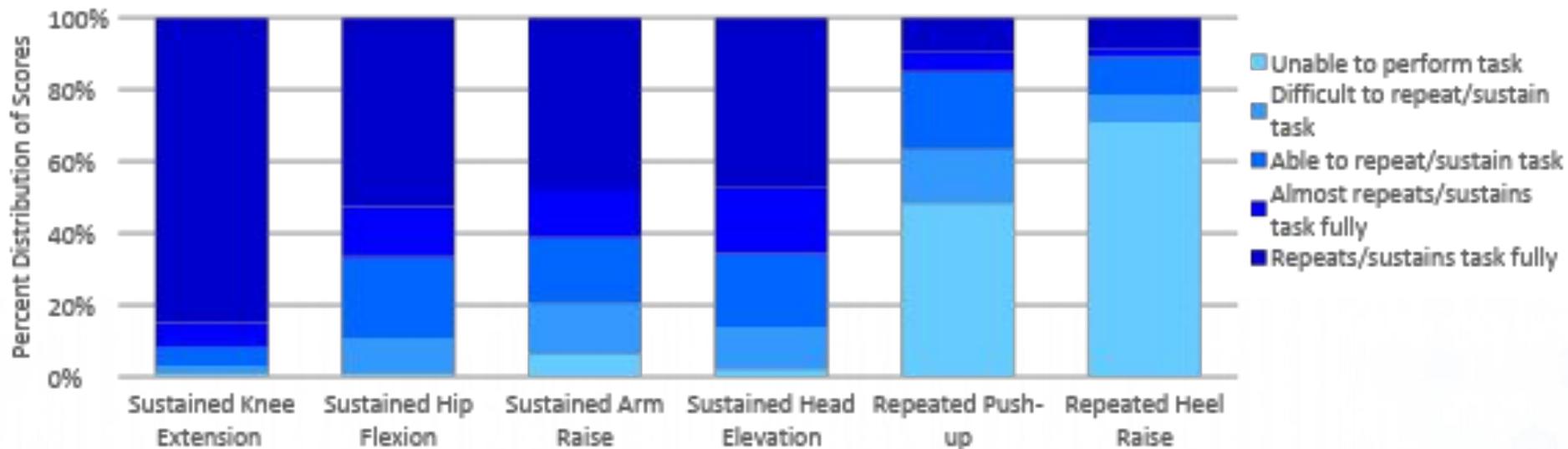
# Exercise Research in Kennedy's Disease

# Muscle Patterns in Kennedy's Disease

| Muscle group       | SBMA percent of healthy control (%) | Muscle Function                    |
|--------------------|-------------------------------------|------------------------------------|
| Upper extremity    |                                     |                                    |
| Lateral pinch      | 48%                                 | Fine hand skills and grip          |
| Elbow flexors      | 42%                                 | Bringing object towards body       |
| Elbow extensors    | 38%                                 | Pushing and bracing falls          |
| Shoulder abductors | 32%                                 | Overhead movements                 |
| Lower Extremity    |                                     |                                    |
| Hip flexors        | 70%                                 | Lifting thigh                      |
| Hip abductors      | 57%                                 | Side-to-side movements and balance |
| Hip extensors      | 48%                                 | Upright mobility                   |
| Ankle dorsiflexors | 45%                                 | Lifting the foot during walk       |
| Knee extensors     | 36%                                 | Upright mobility                   |

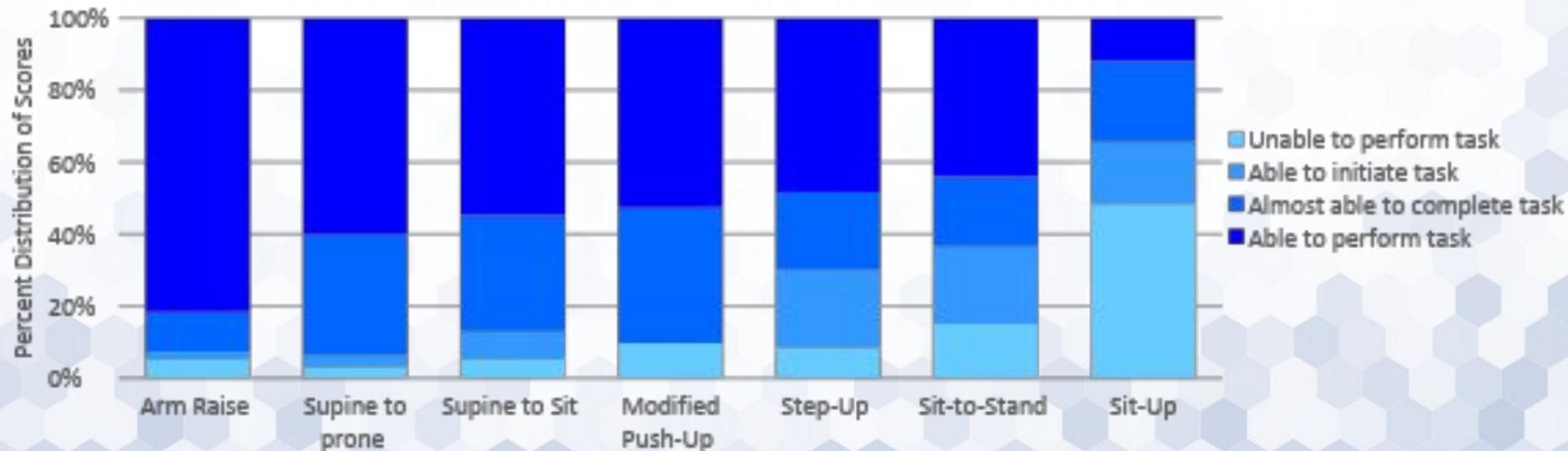
## Endurance Tasks

(Mean = 14.9/21 or 71%)



## Functional Tasks

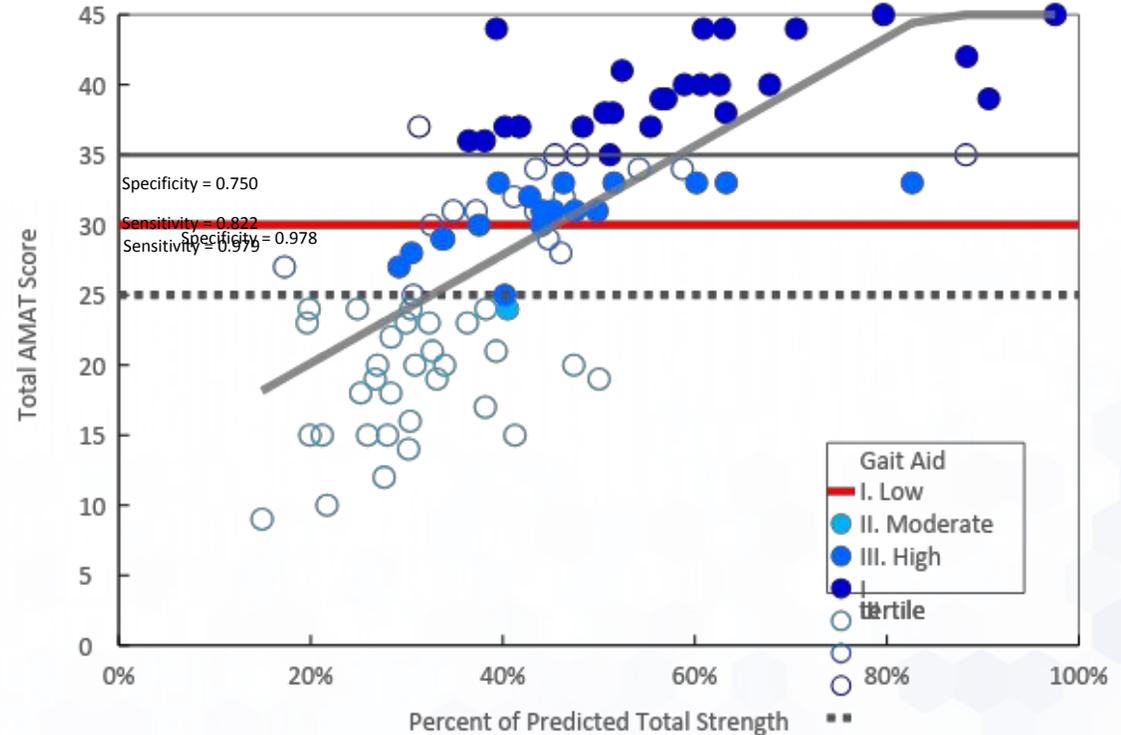
(Mean = 14.42/24 or 71%)



# AMAT and Functional Levels

## AMAT Functional levels

- I. 0 – 24
- II. 25 – 34
- III. 35 – 45



When AMAT < 30, we highly recommend the use of a gait aid ( cane, walker, etc.)

RESEARCH ARTICLE

## A randomized controlled trial of exercise in spinal and bulbar muscular atrophy

Joseph A. Shrader<sup>1,a</sup>, Ilona Kats<sup>2,a</sup>, Angela Kokkinis<sup>2</sup>, Cris Zampieri<sup>1</sup>, Ellen Levy<sup>1</sup>, Galen O. Joe<sup>1</sup>, Joshua G. Woolstenhulme<sup>1</sup>, Bart E. Drinkard<sup>1</sup>, Michaele R. Smith<sup>1</sup>, Willie Ching<sup>1</sup>, Laboni Ghosh<sup>2</sup>, Derrick Fox<sup>2</sup>, Sungyoung Auh<sup>3</sup>, Alice B. Schindler<sup>2</sup>, Kenneth H. Fischbeck<sup>2</sup> & Christopher Grunseich<sup>2</sup>

<sup>1</sup>Rehabilitation Medicine Department, Clinical Center, National Institutes of Health, Bethesda, Maryland

<sup>2</sup>Neurogenetics Branch, National Institute of Neurological Disorders and Stroke, Bethesda, Maryland

<sup>3</sup>Clinical Neuroscience Program, National Institute of Neurological Disorders and Stroke, Bethesda, Maryland

- 12-week “moderate” intensity functional exercise
- This exercise appears to be safe: no complaints/falls
- Response to exercise was slightly greater in those with low initial functional level than those with high functional level

## Effect of aerobic training in patients with spinal and bulbar muscular atrophy (Kennedy disease)

N. Preisler, MD

G. Andersen, BSc

F. Thøgersen, BSc

C. Crone, MD, PhD

T.D. Jeppesen, MD

F. Wibrand, PhD

J. Vissing, MD, PhD

- 12-week moderate intensity cycling program
- No improvement of VO2 max
- Lack of recovery between sessions, worsening of ADL, CK increase
- Significant increase in maximal work capacity (18% increase)
- Significant increase citrate synthase (CS) activity – mitochondria building themselves up



# KD Case Report: Police Officer

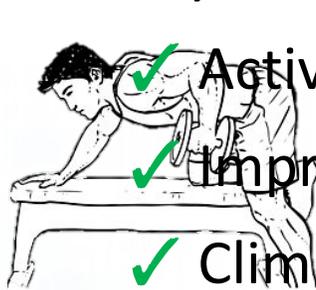
- 56-year-old male police officer diagnosed with Kennedy's disease
  - Diagnosed for 2 years with 41 CAG repeats
  - Changes in his strength and cannot lift weights like he used to
  - Difficulty with stairs, raking the yard, walking long distances, and other daily activities
  - Inability to run, jump or play sports with previous coordination and confidence
- 15-week combined moderate to high intensity exercise program
  - weight lifting (stacked weights)
  - balance training
  - bodyweight functional exercises



# KD Case Report: Police Officer

- 56-year-old male police officer diagnosed with Kennedy's disease

- ✓ Activity age improved from 61 to 53
- ✓ Improved ability to lift weights
- ✓ Climbs stairs, rakes the yard, walks long distances, and completes other daily activities with more ease
- ✓ Able to move with coordination and confidence



Bent Over Row



Arm Flies



Plank



Lunges



Step Ups



Overhead Press



Chest Press



Lateral Pull Down



Knee Extensions



Squat



Single Leg Stand

# Considerations, Precautions, and Adaptive strategies

# Considerations before beginning exercise

- Have a health professional (i.e. physician or physical therapist) evaluate your physical health and functional ability
- Make a list of barriers to your selected exercise and discuss with your health professionals
- Aerobic, strengthening, stretching, and functional exercises should be included as a part of an exercise program
- In addition to exercise, make sure that you are eating and sleeping well and managing stress levels
- Musculoskeletal examinations may reveal problems that are unrelated to Kennedy's disease and may be resolved through therapeutic interventions

# Exercise Challenges and Precautions

## Muscle Overload

- A standard approach when attempting to build muscle that needs to be avoided by those with muscle disorders

## Muscle Overuse

- Repeating and sustaining muscle actions excessively

## Muscle Tears & Trauma

- Causing injury to a muscle

# Exercise Recovery

| Tolerable  | Warning signs   |
|--|---|
| Minimal, dull, tight, or achy feeling at rest, not during exercise | Ache or sharp pain at rest or during exercise         |
| Soreness in the muscles used                                       | Muscle and joint pain                                 |
| Soreness for 2-3 days  | Continual soreness                                    |
| Soreness occurs 24-72 hours after exercise                         | Soreness during exercise or within 24 hours           |
| Soreness improves with movement and stretching                     | Pain doesn't improve with movement; requires ice/rest |

# Recovery is as important as the Exercise

- Refueling: Hydration and Nutrition
- RICE
  - Rest, Ice, Compression, Elevation
- Listen to your Body
  - Recognize increased fatigue, pain, or time needed for recovery
- Cross Training
- Allow your muscles to repair through Sleep
- Reduce Stress with Breathing exercises
- Plan Ahead: Schedule time for exercise and recovery

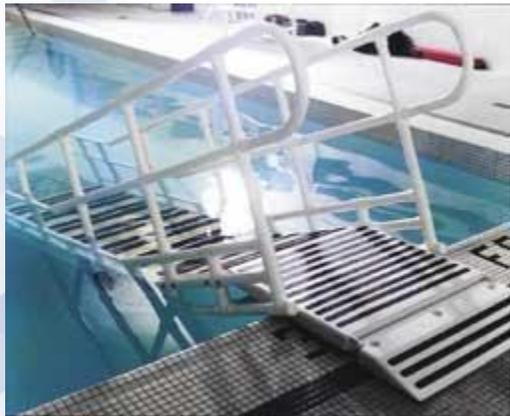


# Exercise Considerations

- NEVER Think “~~No Pain No Gain~~”
  - Muscle overuse may cause irreparable muscle damage
  - Do not exercise through pain or strain
- Quality over Quantity
  - Train at a submaximal intensity to avoid muscle overload
  - Proper Posture, Form, and Technique. Activate the core!
  - Focus on movement control over speed
- Do not focus only on weakest muscles. Exercise and condition all muscles. Think groups of muscles rather than individual muscles

# Adaptive Strategies

Aquatic  
Therapy



Knee  
Brace



Rollator:



4-point  
Cane



Ankle-foot  
Orthosis



Nu-Step

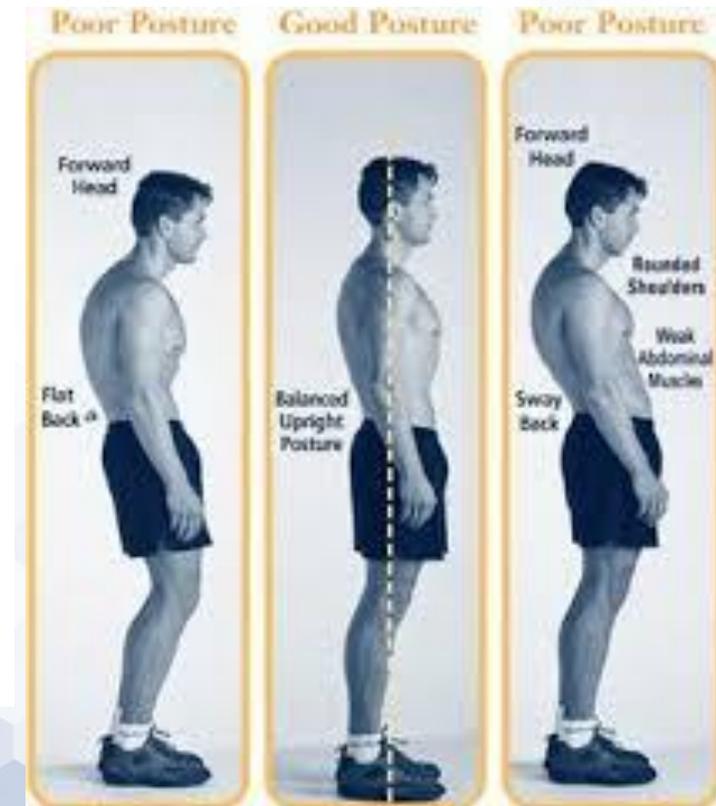
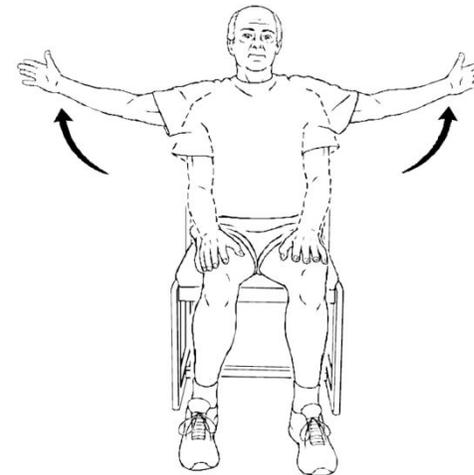
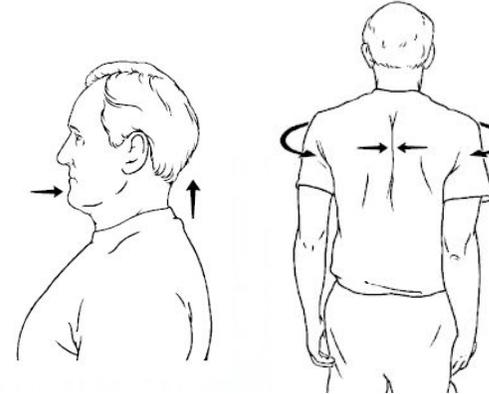
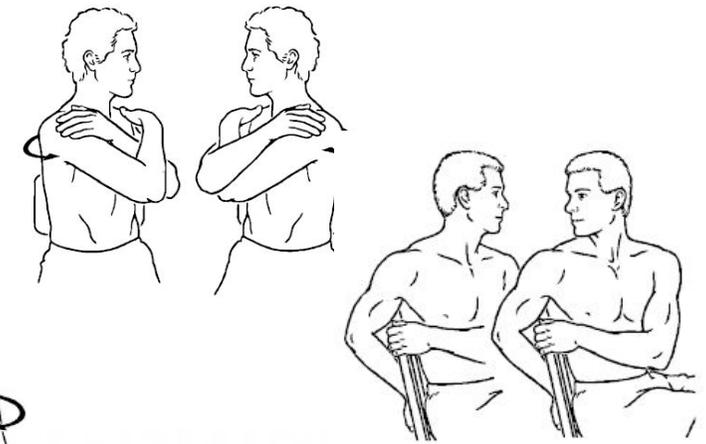


Recumbent Bike



# A Word about Postural Training

- Performance improves as posture does
- “Core” muscles of back, stomach, and hips used
- Low intensity exercise that can be performed anywhere
- Improves respiration and breathing
- Spinal joints receive added stability, reduced pain and stiffness



# Balance Training

## Static Balance on One Foot



One Hand

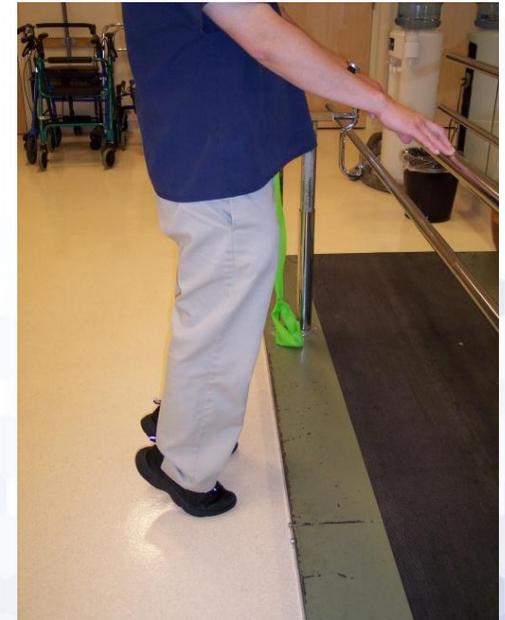


No Hands

## Dynamic Balance



Tandem Stance



Tip toes

# Foot and Ankle Care

# Ankle Strength and Tightness

Helpful Demonstrations:

- Stretch your Achilles tendon
- Test your ankle dorsiflexion strength
- Test your ankle eversion strength
- Test your ankle eversion joint range of motion
- Can you perform a double limb heel raise?

Highly recommend AFO use if you have foot drop

- Foot drop is due to anterior tibialis weakness



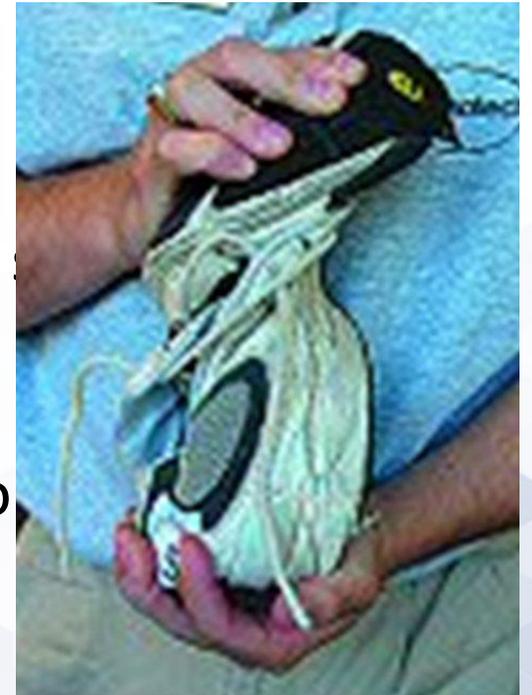
# Qualities of Supportive Shoes

1. Shoe base should be v
2. Sole should be wider
3. As little upper-shoe n
4. The heel counter sho
5. The shoe should NO
6. The shoe should NO
7. Shoe should bend v
8. Shoe should have r



shoe  
e  
an at the  
ag  
e foot o

Avoid



# Recommendations for varying Functional levels

# Muscle patterns in Kennedy's Disease

## Muscles affected early

- Shoulder abductors
- Elbow extensors
- Knee extensors
- Hip abductors

## Muscles to preserve

- Hip extensors (G maximus)
- Hip abductors (G medius)

# Finding your training zone

- Intensity
  - Exercises should be adjustable to be more easy or difficult based on performance and results
  - Use 10 RM for strength and functional training (1RM dangerous)
  - Use talk test or RPE for aerobic training
  - Exercise form is an important intensity feedback
- Frequency: 2-3 times per week
- Exercise should mirror the way we function
  - We function at a submaximal level that is repeatable and sustainable
  - We recommend avoiding sports that involve running, cutting, and high exertion (i.e. tennis, volley ball, etc.)

# Monitoring Exercise

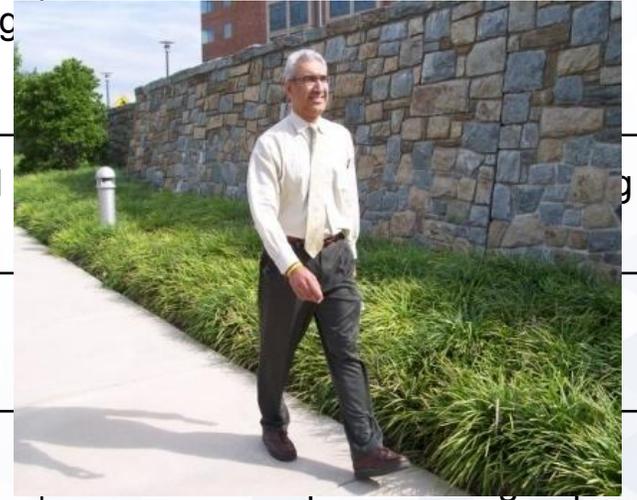
- Jou
- Tra
- Ra

| <i>Rating of Perceived Exertion<br/>Borg RPE Scale</i> |                  |   |
|--|------------------|---|
| 6  |                  | How you feel when lying in bed or sitting in a chair relaxed.<br>Little or no effort. |
| 7  | Very, very light |   |
| 8  |                  |   |
| 9  | Very light       |   |
| 10   |                  |   |
| 11   | Fairly light     |   |
| 12   |                  | Target range: How you should feel with exercise or activity.                          |
| 13   | Somewhat hard    |   |
| 14   |                  |   |
| 15   | Hard             |   |
| 16   |                  |   |
| 17   | Very hard        | How you felt with the hardest work you have ever done.                                |
| 18   |                  |   |
| 19   | Very, very hard  | Don't work this hard!   |
| 20   | Maximum exertion |   |

setbacks

y monitors

| Exercise Elements | Level I<br>Powered mobility   | Level II<br>Gait aid or orthotic use     | Level III<br>No gait aid use        |
|-------------------|---|--|-------------------------------------|
|                   | Level I<br>Powered mobility   | Level II<br>Gait aid or orthotic use     | Level III<br>No gait aid use        |
| Mode of           | hands, active range of motion, active range of motion, functional training on a or at bedside | (ants) or isometric, functional training | Isotonic (free weights), functional |
| Assistance        | None required for most exercise activities  | Gym, clinic, and door activity           |                                     |
| Frequency         | 3 times/week, once or twice per day   | once per day                             |                                     |
| Sets              | 3 sets per muscle group   | 3 muscle group                           |                                     |
| Reps              | 10 - 15   | 10 - 12                                  | 8 - 10                              |



# Level III: Patients Who Don't Use a Gait Aid

## Isotonic Free Weights



## Core Strengthening



## Hip Strengthening



# Level II: Patients Who Use a Gait Aid

## Shoulder, Elbow & Wrist with Bands



## Stretching

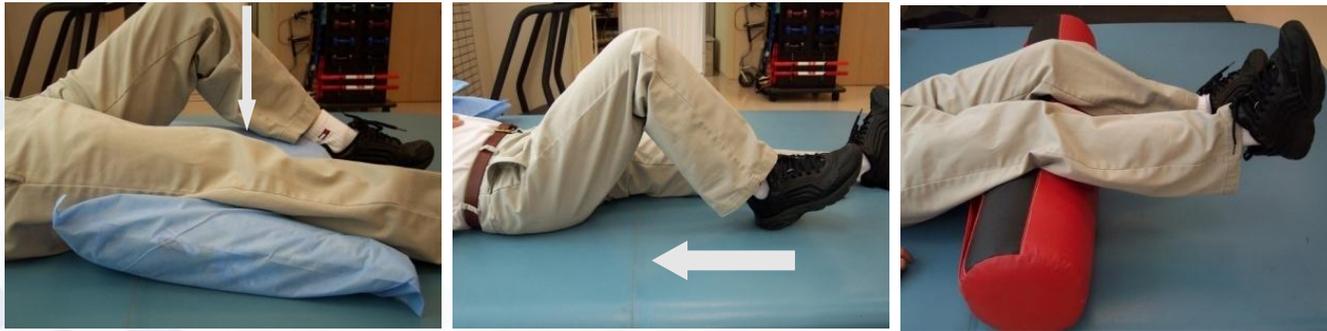


## Leg Resistance Training



# Level I: Patients Who Use Powered Mobility

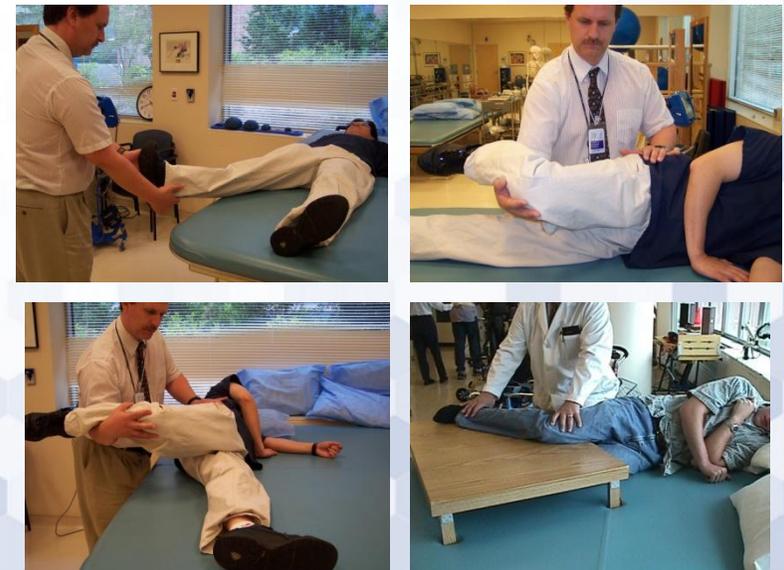
Isometric, Active Range of Motion



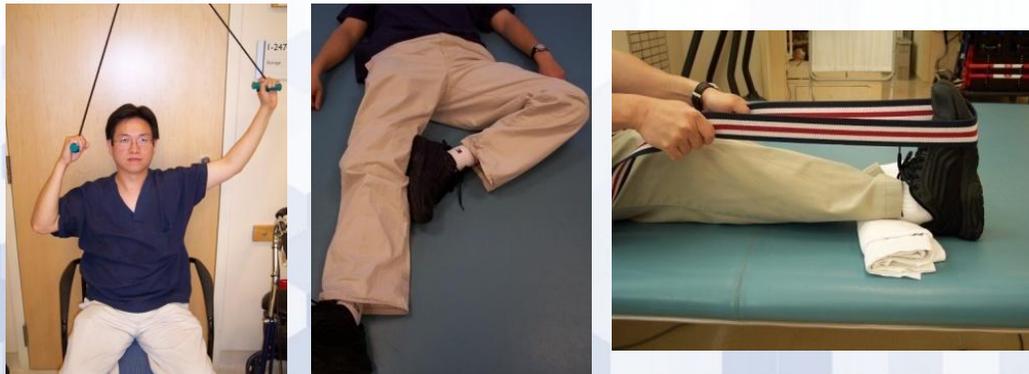
Reaching with Table Assist



Active Assistive to Resistive



Flexibility



# Turn A Towel Into A Home Gym



# Flexibility: Range of Motion is Critical

- Muscle Tightness negatively affects range of motion and function
- Prolonged sitting can result in tight hip flexors, which affect walking posture and hip extensor strengthening



# Examples Of Function Specific Training Exercises



Sit to Stand



Stairs



Rolling



Supine to Sit

# Summary

1. Avoid inactivity
2. Have a health professional evaluate your physical health before beginning an exercise program
3. Monitor all that you can and communicate with care provider and health professionals about responses to exercise
4. Exercise intensity can be adjusted up/down to fit every functional level and also when gains or setbacks occur
5. Do not work until exhaustion and do not exercise through pain
6. Exercise safely in an appropriate environment with stable supports
7. Posture and form is key to any activity, especially exercise

# Acknowledgements



Galen O. Joe, MD



Angela Kokkinis, RN

Chris Grunseich, MD

Kirk H. Fischbeck, MD

# Questions & Answer



***Thank You for your attendance***

# Strength and Function: Reserve Capacity

