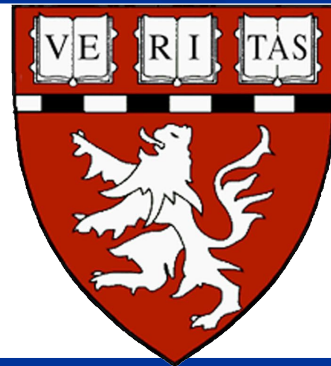


# Nutrition in ALS: How to EAT MORE!

*Presented by:*

Anne-Marie A. Wills, M.D., M.P.H.

Jane L. Hubbard M.S., R.D., L.D.N.



# Meet Today's Expert Panelists

Anne-Marie A. Wills,  
M.D., M.P.H.

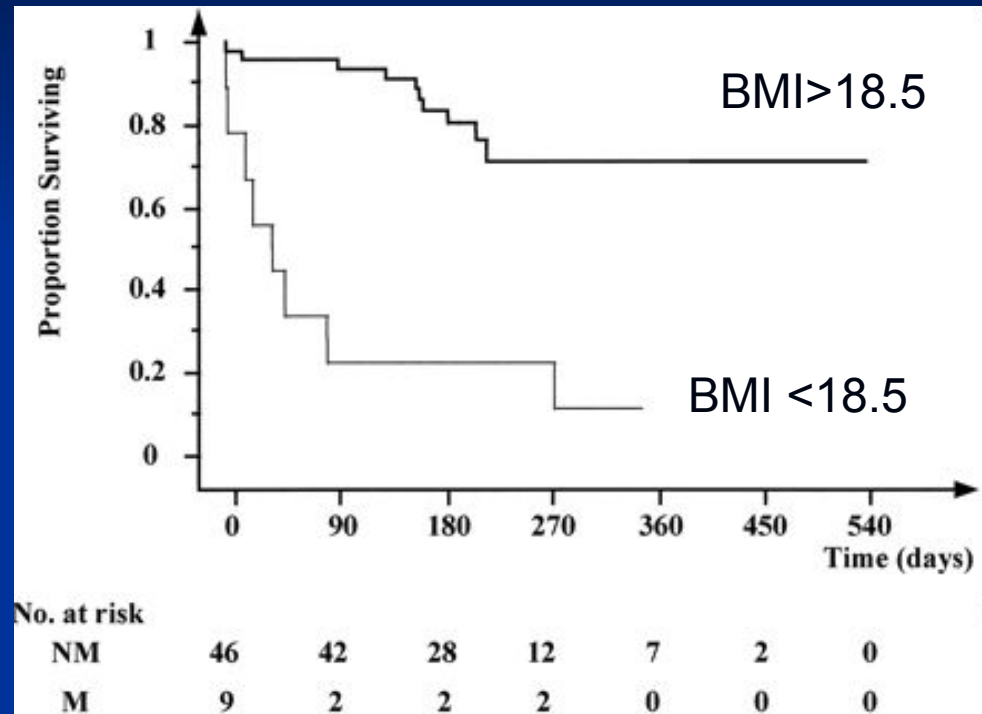


Jane Hubbard,  
M.S., R.D.



# Weight Loss and ALS

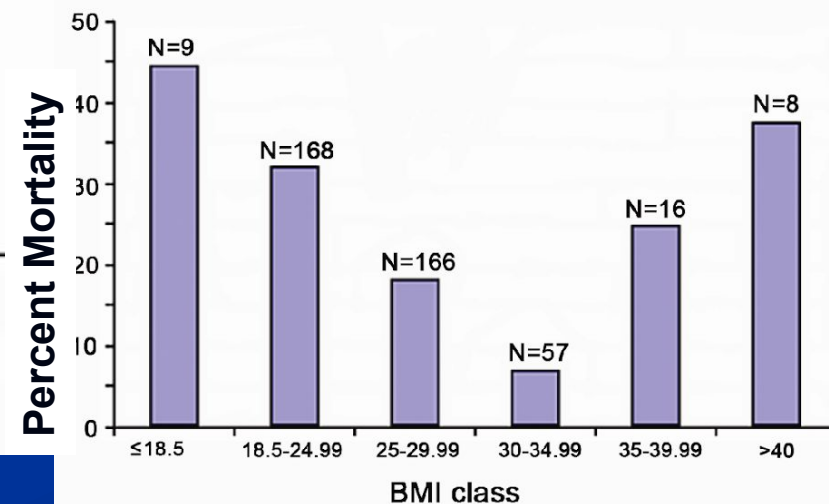
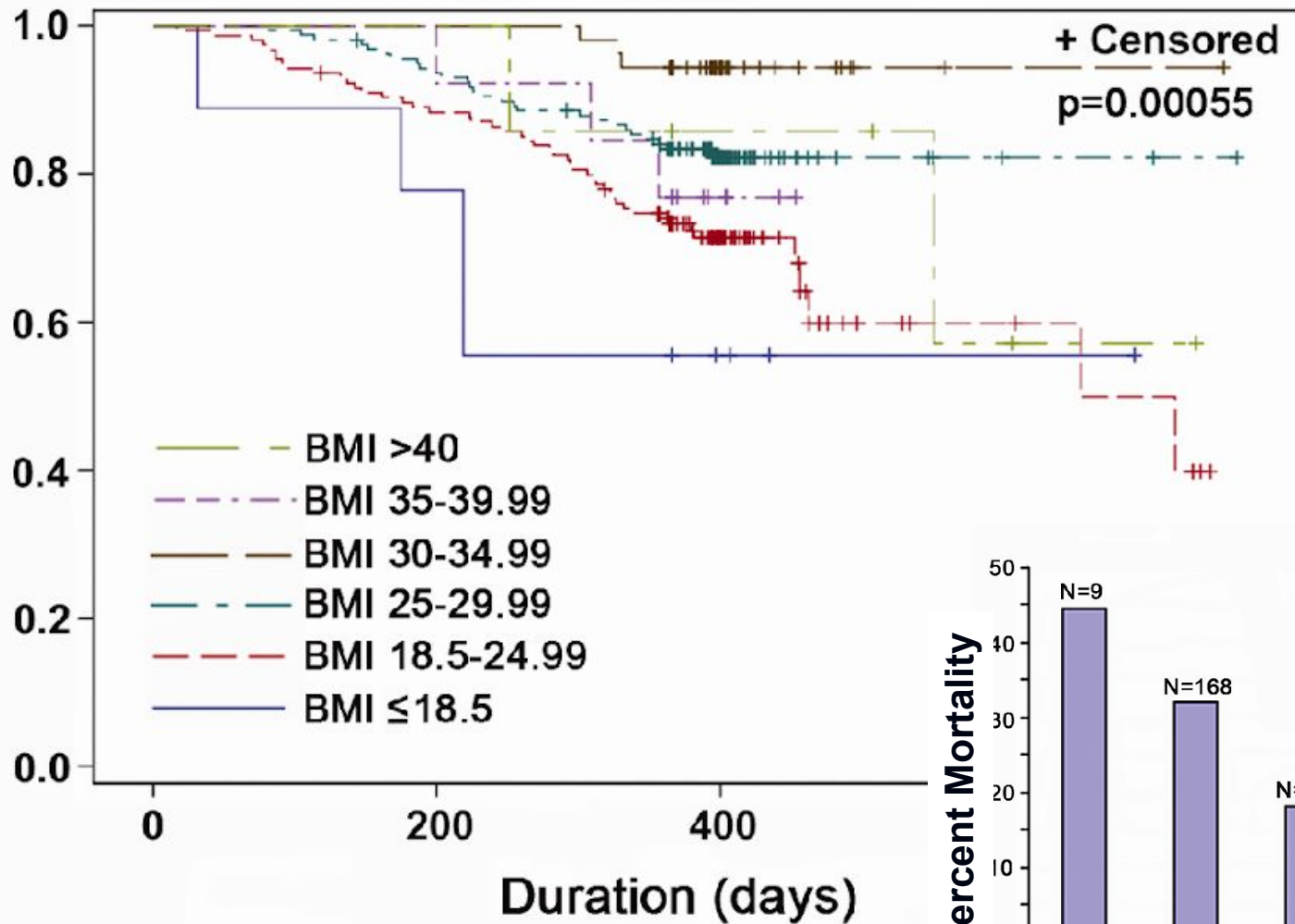
- Body Mass Index (BMI) is a measure of weight/height.
- Being underweight (BMI<19) is associated with reduced survival in ALS



Desport, *Neurology* 1999

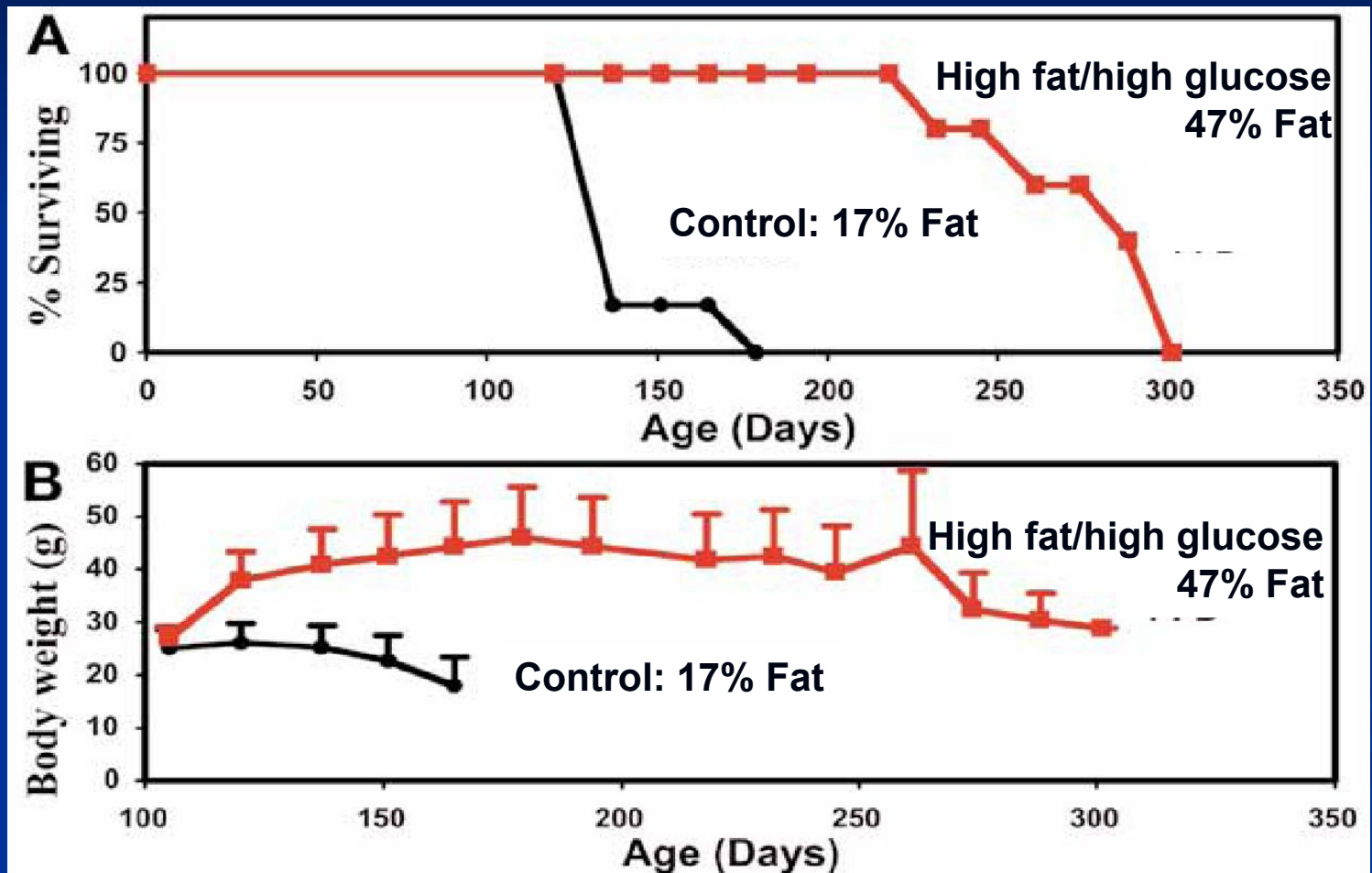
# Survival by BMI category in ALS

Survival Probability



Paganoni et al. 2011

# Survival increased in G93A mice



- Mattson, *Neuromolecular Medicine* 2007

# Hypercaloric enteral nutrition in patients with amyotrophic lateral sclerosis: a randomised, double-blind, placebo-controlled phase 2 trial

Anne-Marie Wills, Jane Hubbard, Eric A Macklin, Jonathan Glass, Rup Tandan, Ericka P Simpson, Benjamin Brooks, Deborah Gelinas, Hiroshi Mitsumoto, Tahseen Mozaffar, Gregory P Hanes, Shafeeq S Ladha, Terry Heiman-Patterson, Jonathan Katz, Jau-Shin Lou, Katy Mahoney, Daniela Grasso, Robert Lawson, Hong Yu, Merit Cudkowicz, for the MDA Clinical Research Network\*



30 ALS  
Subjects  
with  
PEG/RIG  
Randomized 1:1:1



10 subjects Jevity 1.0  
(replacement calories)



10 subjects Jevity 1.5  
(1.25 x TDEE)



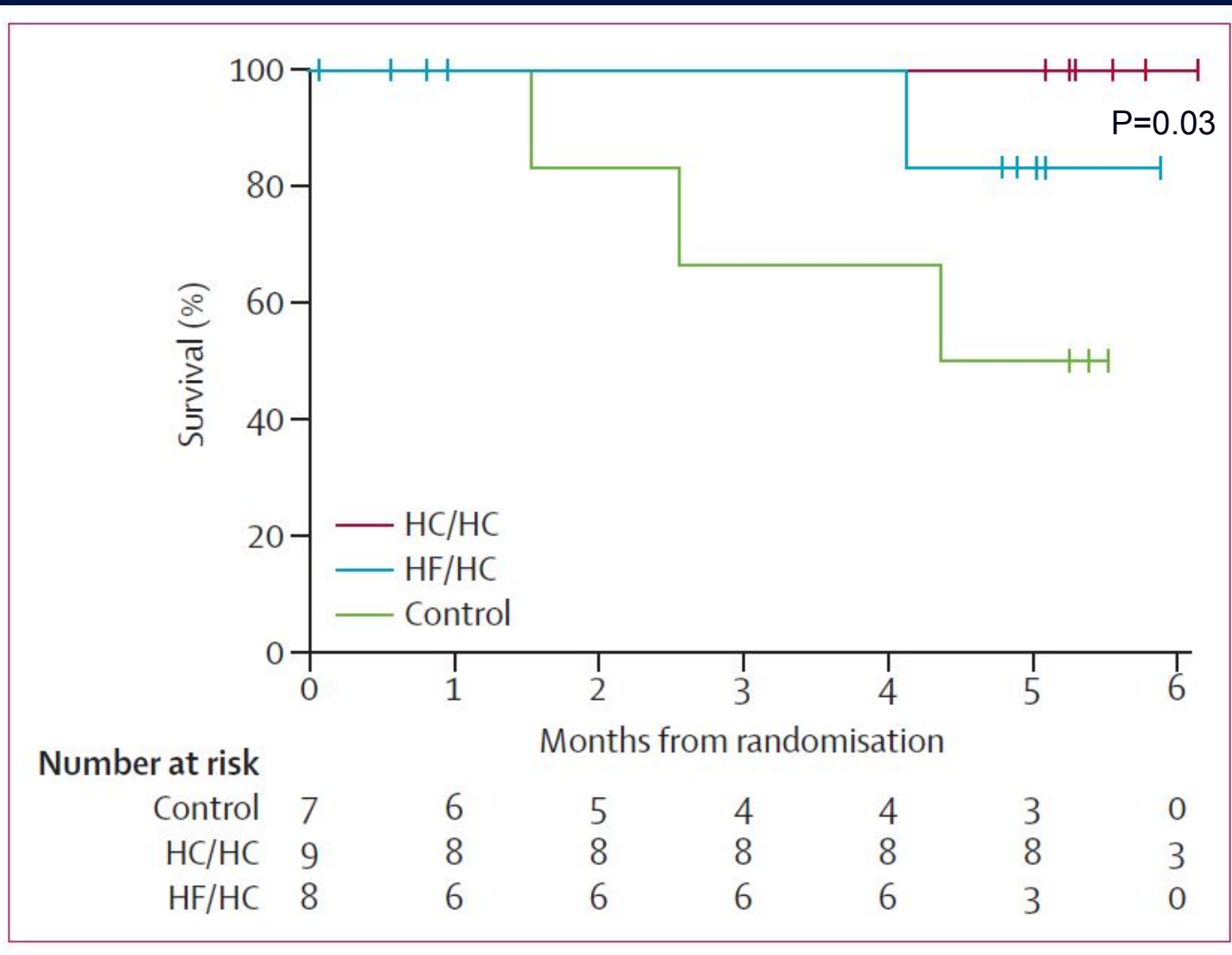
10 subjects Oxepa  
(1.25 x TDEE using 55%  
fat calories)

4 month study diet intervention





# Survival Data



# EAT MORE Study

Electronic-health

Application

To

Monitor

Outcomes

REmotely



# EAT MORE Study Design



# mHealth App

- NuPlanit App for iPhone or iPad.
- Participants received iPad for duration of study
- App provided customized dietary goals
- Participants were prompted automatically to enter their dietary intake x 4 days and weights x 2 days, every 2 weeks
- RD (Jane Hubbard) could message participants directly through the application to provide recommendations and reminders



# Nutrition Goals

- In-Person and App arms received personalized goals using Kasarskis Equation (Kasarskis et al. AJCN, 2014)

Baseline BMI	Self-reported weight change since diagnosis	Weight goal during study	Calorie Goals/day
<25	Positive or negative	+1 kg/month	Deficit +235 Kcal
25≤30	<5% of body weight lost	+0.5 kg/month	Deficit +117.5 Kcal
25≤30	>5% of body weight lost	+1 kg/month	Deficit +235 Kcal
30-35	<5% of body weight lost	Weight Stability	Deficit +0 Kcal
30-35	>5% of body weight lost	+0.5 kg/month	Deficit +117.5 Kcal
>35	Positive or Negative	Weight Stability	Deficit + 0 Kcal

# Kasarskis Equation

- Men

$$(66 + (13.7 * \text{weight}) + (5 * \text{height}) - (6.76 * \text{age})) + (55.96 * \text{ALSFRS6 score}) - 168$$

- Women

$$(665 + (9.6 * \text{weight}) + (1.8 * \text{height}) - (4.7 * \text{age})) + 55.96 * \text{ALSFRS6 score} - 168$$

- Weight in kg
- Height in cm
- Age in years

- ALSFRS-6 (cumulative score of 6 questions)
- Kasarskis et al. Am J Clin Nutr. 2014 Apr;99(4):792-803.

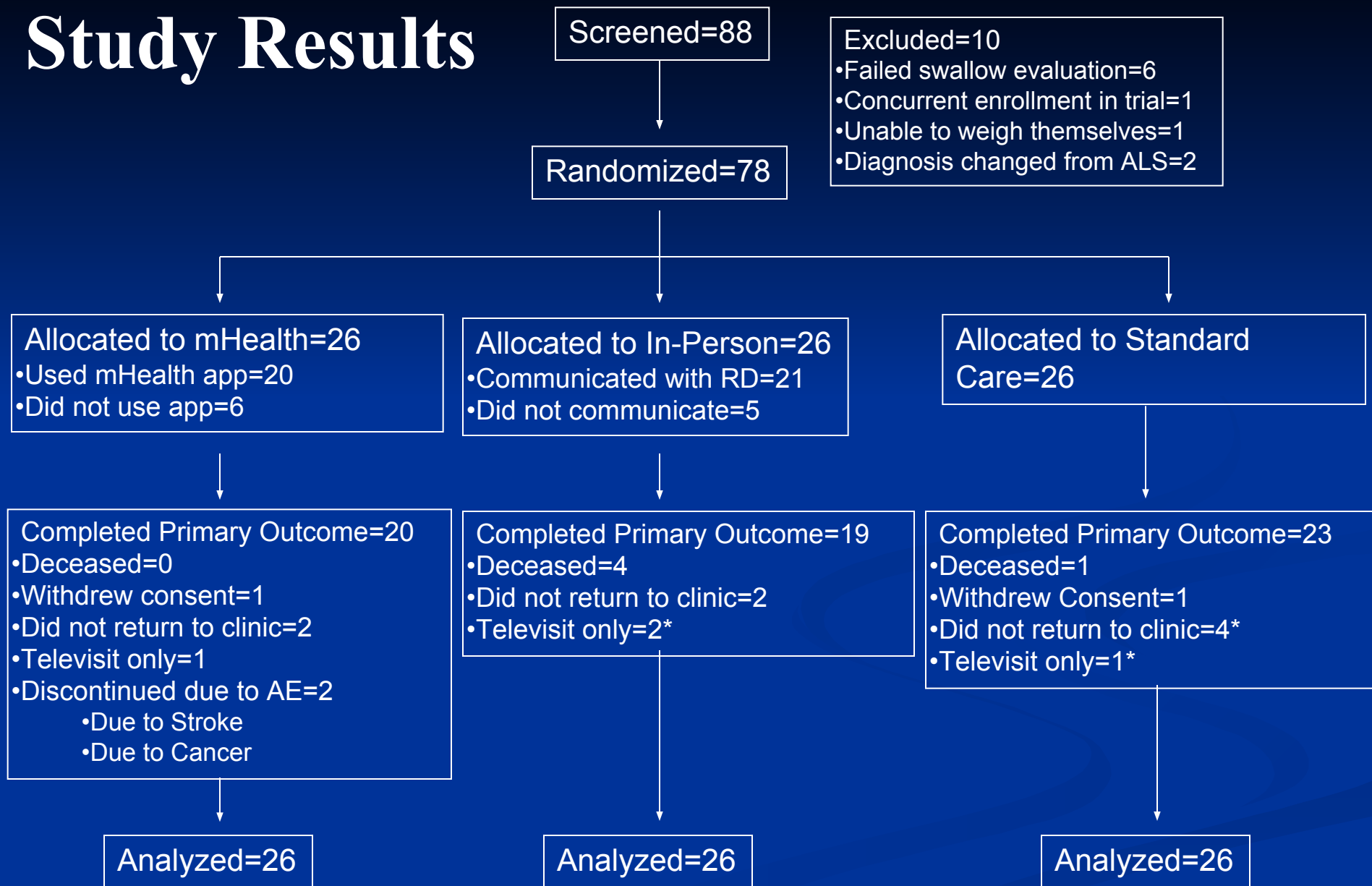
# ALS Functional Rating Scale (ALSFERS-6)

- Question 1: Speech
- Question 4: Handwriting
- Question 6: Dressing and Hygiene
- Question 7: Turning in Bed/Adjusting Bed Clothes
- Question 8: Walking
- Question 10a: Dyspnea

# Example of Kasarskis Calculation

- Age: 60 years old
- Sex: male
- Weight: 180 lbs
- Height: 5' 10" (70")
- ALSFRS-6 Score: Score 19 of 24
  - Speech: 4
  - Handwriting: 2
  - Dressing: 2
  - Turning in Bed: 3
  - Walking: 4
  - Dyspnea: 4
- Harris-Benedict BMR= 1670 kcal
- Adjust for ALS functional status:  $(55.96 \times \text{ALSFRS-6 score}) - 168 = 895 \text{ kcal}$
- Total Estimated Daily Caloric Need=  $1670 + 895 = 2565 \text{ kcal}$

# Study Results



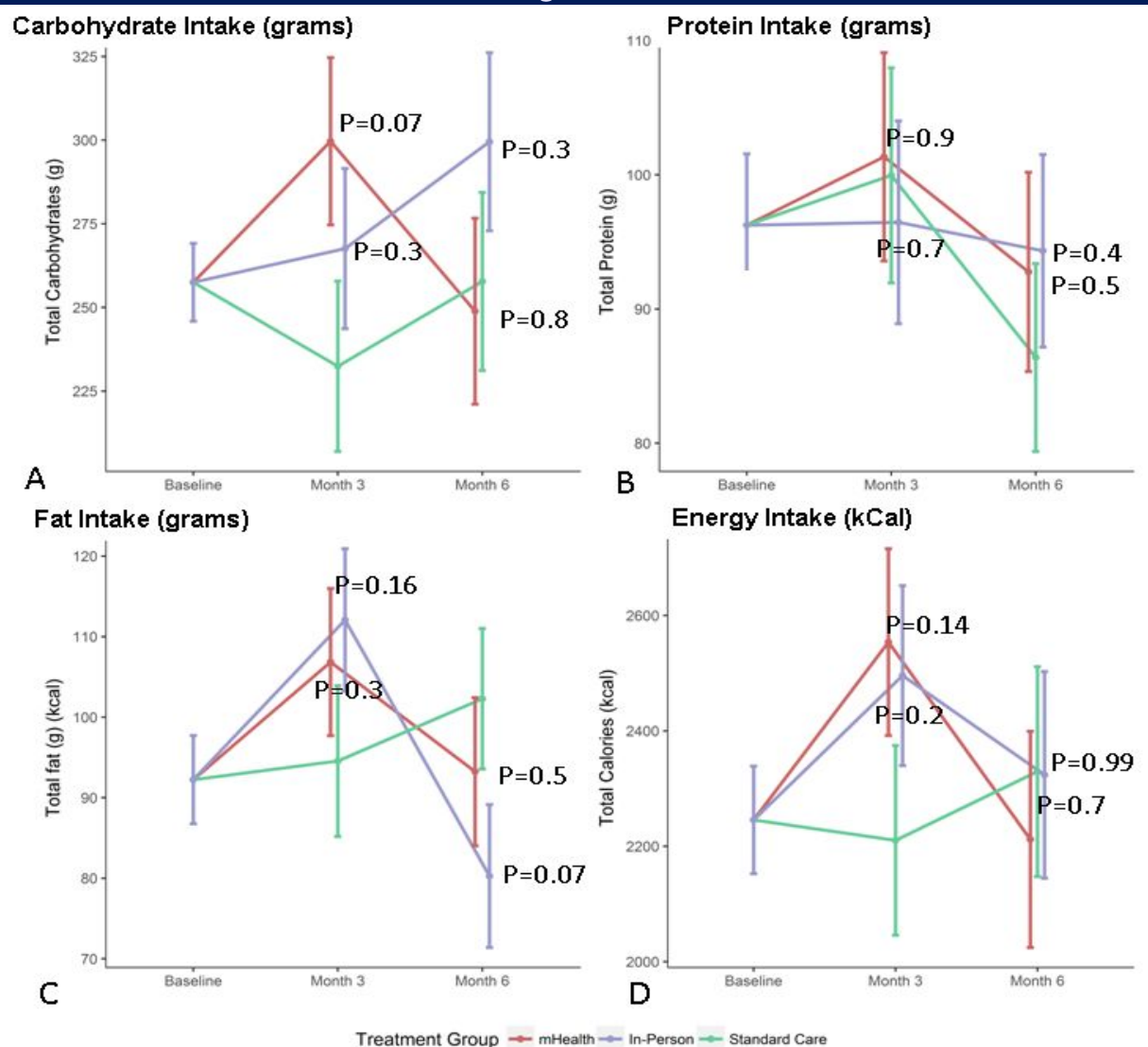
\*Provided weight and/or ALSFRS-R remotely



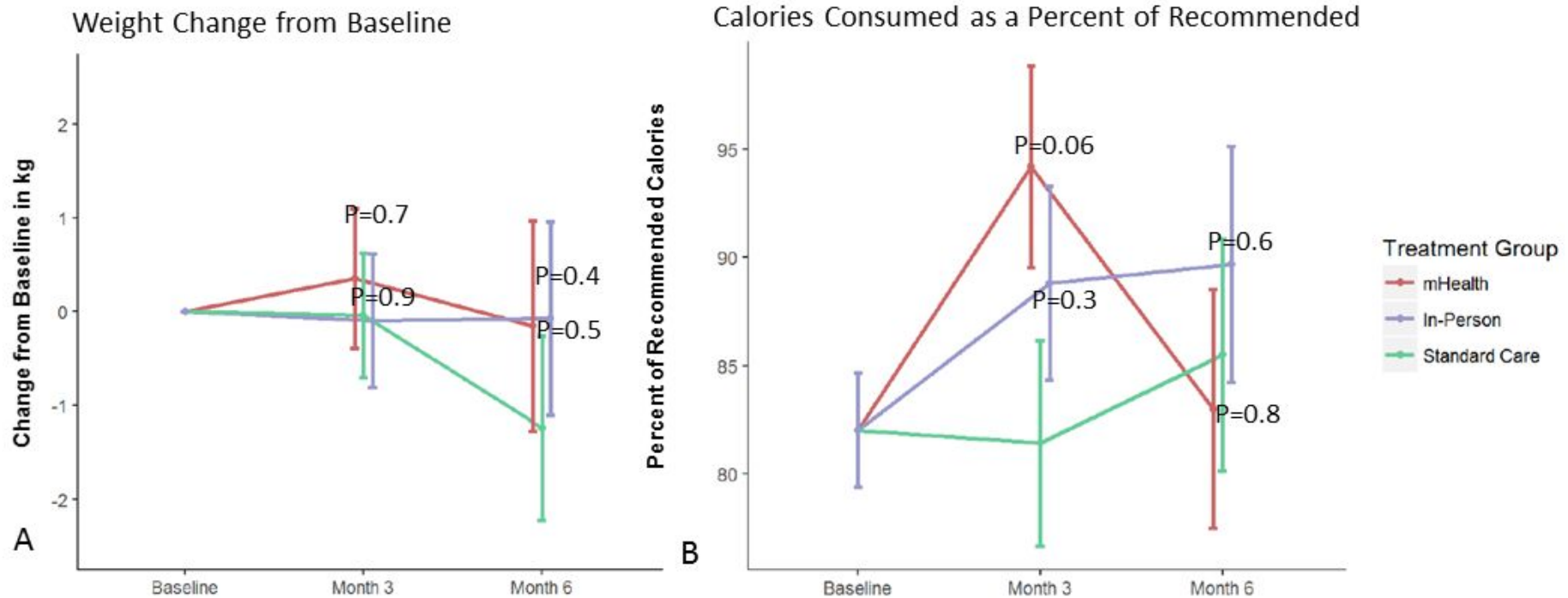
# Baseline Characteristics

	Standard Care N=26	In-person N=26	mHealth N=26	Overall p-value
Male N(%)	11 (42.3%)	16 (61.5%)	20 (76.9%)	0.04
Age (mean±SD yrs)	57.5±10.9	58.5±11.9	54.7±11.5	0.47
Bulbar Onset N(%)	3 (11.5%)	2 (7.7%)	4 (15.4%)	0.69
ALSFRS-R (mean±SD)	36.7±5.4	34.9±6.7	37.4±6.2	0.35
Months since symptom onset (mean±SD)	22.3 (18.0)	26.1 (16.8)	27.1 (18.9)	0.60
BMI (mean±SD kg/m <sup>2</sup> )	26.8±5.1	25.7±4.1	26.0±4.5	0.70
Weight loss since diagnosis (mean ±SD kg)	3.4±5.5	6.3±7.1	2.1±3.4	0.03

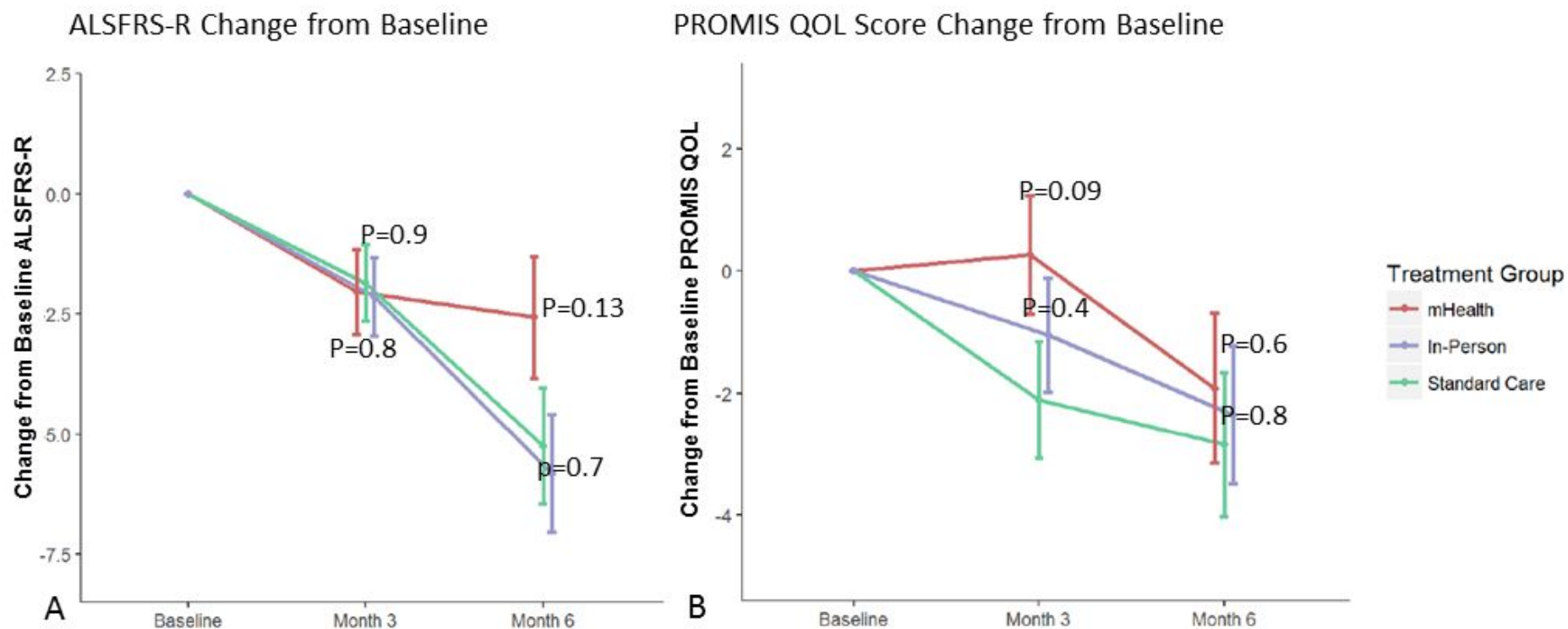
# Effects of Nutritional Counseling on Dietary intake



# Change in Weight and Calories



# Change in Secondary Outcomes



# Summary

- Nutritional counseling with a mHealth app led to greater dietary compliance than nutritional counseling alone
- Counseling with an mHealth app led to greater weight stability, although not significantly different
- Counseling with an mHealth app led to improved ALSFRS-R and QOL using PROMIS
- Next steps?

# ALS Nutrition App

- Nutritional Goals
- Tips to eat more calories
- Example Recipes
- Monitor your symptoms
  - Screen for swallowing problems
  - Monitor your ALSFRS-R progression
  - Notify providers
- Perform tasks for research



# Bitesnap App

- Simply photograph your food
- Bitesnap will recognize what you are eating
- Tell Bitesnap how much you ate
- Bitesnap will calculate how many calories you ate
- Bitesnap will send those calorie results to Apple Healthkit or GoogleFit





# Interested in Participating?

- Patient and caregiver volunteers will be needed to
  - Beta test the app
  - Publicize the app
  - Enroll in a research study using the app
  - If interested, please contact:
    - Mansi Sharma
      - Phone: (508) 395-3479
      - Email: [msharma13@mgh.harvard.edu](mailto:msharma13@mgh.harvard.edu)

# Healthy Eating in ALS



Jane Hubbard MS, RD, LDN, CBDT  
Metabolism & Nutrition Research  
Massachusetts General Hospital

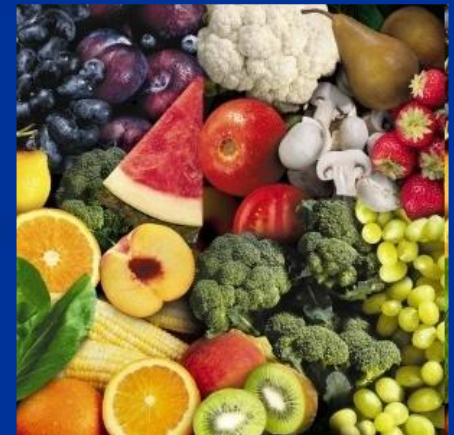
# Overview

- Nutrition Management in ALS
  - Your Team
  - Your Numbers
- Calculating Daily Calorie Requirements
- Weight Gain/Maintenance Techniques
  - Food Group Recommendations
  - High Calorie Suggestions
  - Symptom Management



# Nutrition Management in ALS

- Current research suggests that it is important to prevent weight loss in patients with ALS
- Maintaining and/or gaining weight may help increase the length and quality of your life
- A well balanced diet is essential to maintaining body composition (preserving muscle mass and body fat stores) – this is the goal



# Nutrition Management in ALS

- Assessing calorie needs in people with ALS is very complex
- Weight loss and subsequent malnutrition is very common and may be due to:
  - Loss of appetite
  - Dysphagia
  - Difficulty feeding
  - Increased metabolism
  - Other symptoms



# Nutrition Management in ALS



# Nutrition Management in ALS

## Your Team

- Physician (MD)
- Registered Nurse (RN)
  - Coordinate your medical care





# Nutrition Management in ALS

## Your Team

- Physical Therapist (PT)
  - Determine safe exercise and stretching habits and help you obtain necessary splints



# Nutrition Management in ALS

## Your Team

- Occupational Therapist (OT)
  - Evaluate the need for assistive devices for eating and drinking
  - Offer tools and techniques to grip utensils and assist with eating



# Nutrition Management in ALS

## Your Team

- Speech-Language Pathologist (SLP)
  - Swallow evaluation/food texture modification
  - Determine your safe food consistency



# Nutrition Management in ALS

## Your Team

- Registered Dietitian (RD)
  - Determine Calorie (energy) and Fluid Needs
  - Complete Body Measurements
    - Height/weight/waist/hip/BMI
  - Provide Appropriate Diet/Recipes Suggestions
  - Assist with Symptom Control



# Know Your Numbers

- Simple measurements and calculations

- Height
- Weight (invest in a home scale)
- BMI Calculation – aim for a BMI of  $>30$ 
  - $\text{kg} / \text{m}^2$
  - $\text{lb} / (\text{inches}^2) \times 703$
  - Online Calculator



[http://www.nhlbi.nih.gov/health/educational/lose\\_wt/BMI/bmicalc.htm](http://www.nhlbi.nih.gov/health/educational/lose_wt/BMI/bmicalc.htm)

# Determining Calorie Requirements

## Predictive Equations

- Mifflin-St Jeor Formula

Men:  $\text{RMR} = 9.99 \times \text{weight} + 6.25 \times \text{height} - 4.92 \times \text{age} + 5$

Women:  $\text{RMR} = 9.99 \times \text{weight} + 6.25 \times \text{height} - 4.92 \times \text{age} - 161$

- Harris Benedict Equation

Men:  $\text{RMR} = 66.47 + 13.75 \times \text{weight} + 5.0 \times \text{height} - 6.75 \times \text{age}$

Women:  $\text{RMR} = 655.09 + 9.56 \times \text{weight} + 1.84 \times \text{height} - 4.67 \times \text{age}$

Height (cm)   Weight (kg)   Age (years)

# Determining Calorie Requirements

- Use predictive equations with an ALS factor to calculate how many calories you need
- Kasarskis Calculator:
  - Men  $(66 + (13.7 * \text{weight}) + (5 * \text{height}) - (6.76 * \text{age})) + (55.96 * \text{ALSFRS6 score}) - 168$
  - Women  $(665 + (9.6 * \text{weight}) + (1.8 * \text{height}) - (4.7 * \text{age})) + 55.96 * \text{ALSFRS6 score} - 168$ 
    - Weight in kg
    - Height in cm
    - Age in years
    - ALSFRSr (cumulative score of 6 questions)



# Determine Current Calorie Intake

- Determine the number of calories you are consuming now
  - Use the 24 hour recall method or
  - Use the 4 day food record method
    - Work with your Dietitian to determine your current calorie intake
    - Try a food & calorie smart phone app to give you an estimate of your current calorie intake – check out <http://www.wellocracy.com/food-calorie-trackers/>

# Make up the difference

- Add more calories to promote weight gain
  - 3500 calories = 1 pound (rule of thumb)
    - 3500 calories / 7 days = 500 extra calories per day
  - To gain 1 lb/week, add an extra 500 calories per day
  - Too fast?, add 250 calories per day to gain  $\frac{1}{2}$  pound per week.



# Weight Gain Recommendations

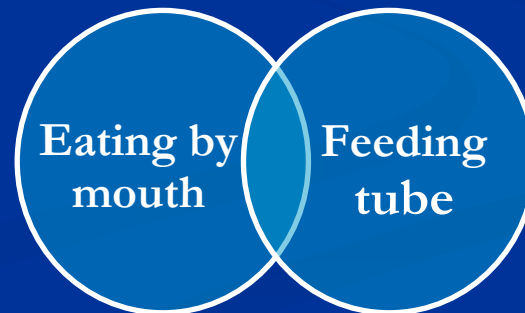
- Gaining weight is all about increasing the number of calories you consume in relation to the amount of energy you expend
- Eating more calories than your body needs will tip the scales
- Aim for slow and steady weight gain
  - .5 to 1 pound per week



# Weight Gain Recommendations

add 250-500 calories per day

- Food Only – add calories to foods
- Supplements – add commercial drinks or make your own smoothies
- Tube Feeding – supplement your intake with a nighttime tube feeding.



# Example Calculation

## Example

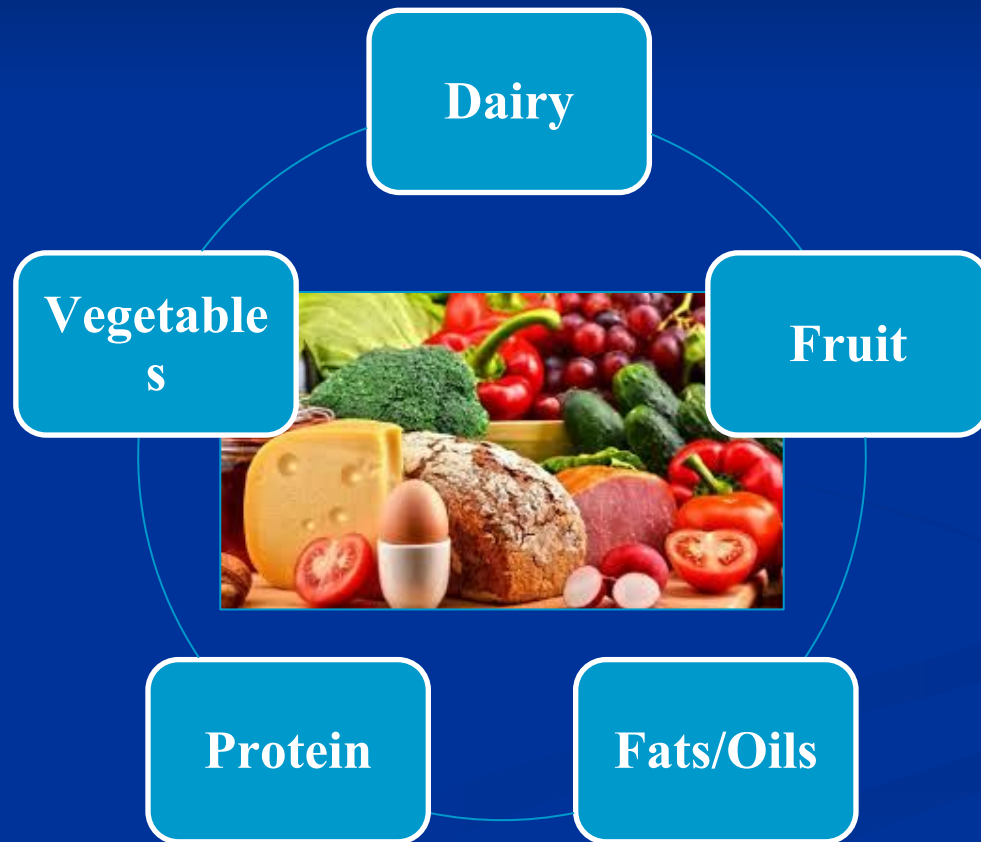
Daily Calorie Requirements (calories/day)	Current Calorie Intake (phone app)	Difference	BMI Value	BMI Goal
2600	1800	800 deficit	20	25-30

- 800 calorie deficit
- Add 800 calories just to maintain current weight
- Low BMI – Add more calories to gain weight
  - 3500 calories = 1 pound (rule of thumb)
  - Add an extra 125-250 calories per day to gain 1-2 pounds per month



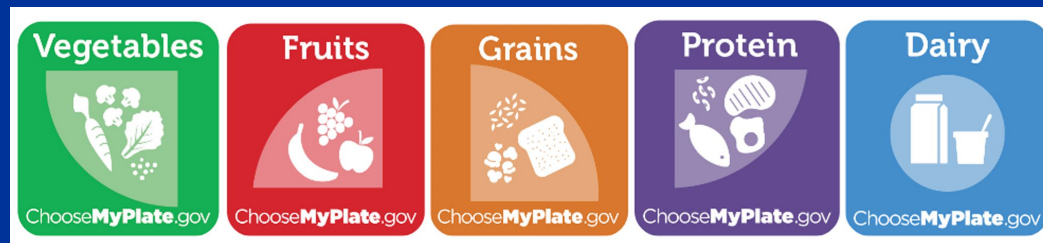
# Weight Gain Techniques

Keep it healthy. Choose foods from **all 5** food groups



# Weight Gain Techniques

- Separate calories into food groups and consume colorful foods to ensure that you get what you need in terms of macronutrients and micronutrients



- If your base calories come from the 5 food groups and are within the recommended amount, your extra calories can come from whatever feels right

# What 1800 Calories Looks Like

Food Group	Serving
Dairy (milk, yogurt)	3 cups
Protein (meat, fish, poultry/eggs/ nuts/seeds)	5 oz.
Fruit	2 cups
Vegetables	2.5 cups
Grain (bread, rice, pasta)	6 oz. (equivalents)
Fat (oils, butter)	4 tsp
Treats	1





Food Item	Food Group Category	Calories
Instant Oatmeal Prepared with Water (1 packet)	G	165
Low Fat Milk (4oz)	D	50
Wheat Toast (1slice) with Jelly (1 tsp)	G/O	85
Orange Juice (8oz)	F	110
Tuna Sandwich (1/2 can, water packed) w/mayo/lettuce/tomato slices	G/P/O/V	340
Fresh Banana	F	75
Low Fat Milk (8oz)	D	100
Grilled Chicken Breast (3oz)	P	145
Baked Potato (medium) with butter (1 tsp)	G/O	150
Steamed Mixed Vegetables (1.5 cup)	V	85
Chocolate Ice Cream (1 cup)	Treat/D	285
Low Fat Yogurt (6oz) and Berries (3/4 cup)	D/F	210
Total Calories		1800

**D = dairy**  
**F = fruit**  
**V =**  
**vegetable**  
**G = grain**  
**P = protein**  
**O = oil/fat**

# What 2600 Calories Looks Like

Food Group	Serving
Dairy (milk, yogurt)	3 cups
Protein (meat, fish, poultry/eggs/ nuts/seeds)	6.5 oz.
Fruit	2 cups
Vegetables	3.5 cups
Grain (bread, rice, pasta)	10 oz. (equivalents)
Fat (oils, butter)	4 tsp
Supplement (240 calories)	1



# Adding Calories with Food

Carbohydrate Foods	Protein Foods	Fats and Oils
4 calories per gram	4 calories per gram	9 calories per gram



# Adding Calories with Food

Food Item	Calories	Protein	Fat	CHO
Butter TB	102	0.12	11.5	.009
Margarine TB	100	.023	11.1	.099
Mayo TB	94	.132	10.3	.078
Olive Oil TB	119	0	13.5	0
Canola Oil TB	120	0	13.6	0
Corn Oil TB	123	0	13.6	0
Avocado Oil TB	120	0	13.6	0

**CHO = carbohydrate**

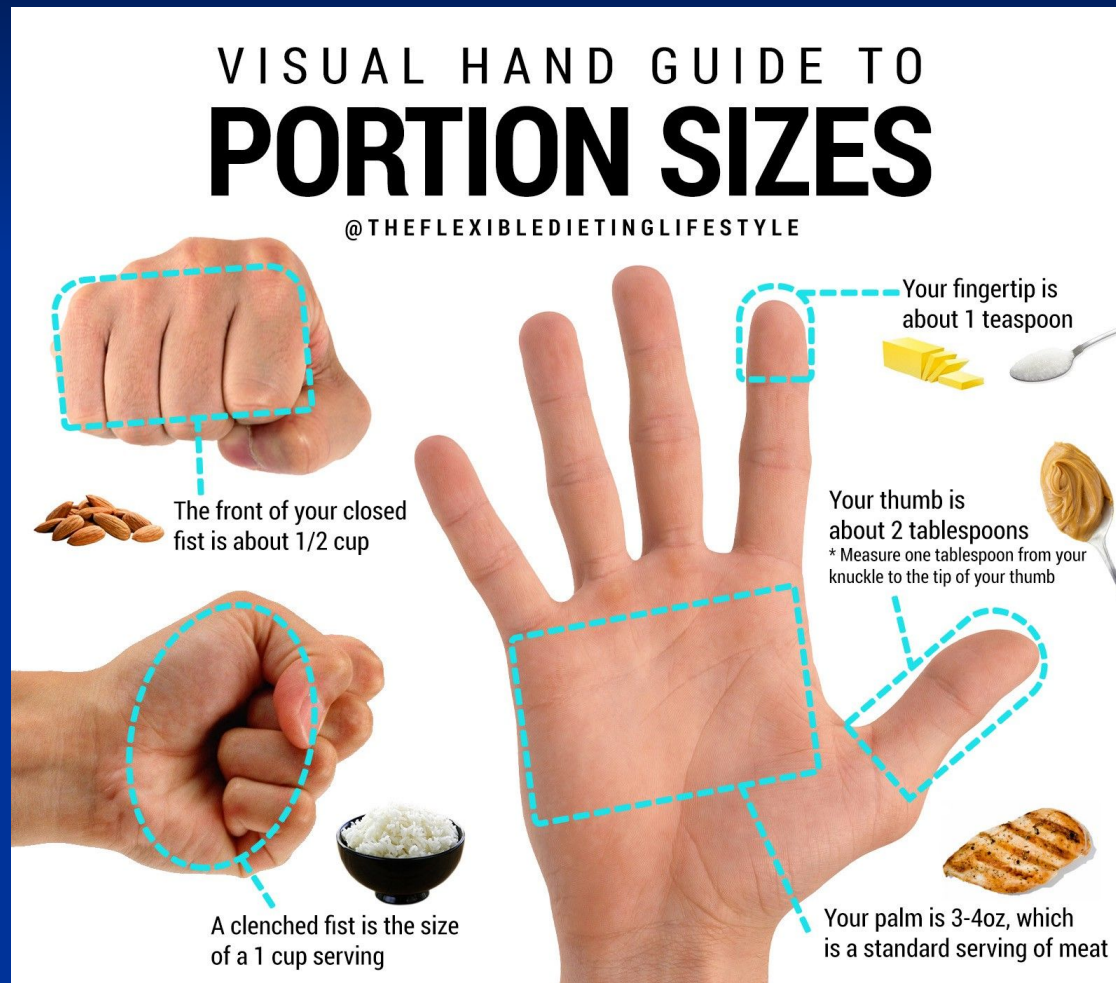
# Adding Calories with Food

Food Item	Calories	Protein gm	Fat gm	CHO gm
Avocado 1/2	114	1.3	10.5	5.9
Peanut Butter 2TB	193	7.2	16.6	7.2
Almond Butter 2TB	192	6.6	17.3	5.9
Cashew Butter 2TB	188	5.6	15.8	8.8
Peanuts 1/4cup	214	8.9	18.1	7.8
Walnuts 1/4cup	191	4.5	19.1	4.0
Almonds 1/4cup	206	7.2	18.1	7.2
Hazelnuts 1/4cup	218	5.1	21.1	5.9

# Adding Calories with Food

Food Item	Calories	Protein	Fat	CHO	Calcium	Vitamin D mcg
Yogurt (whole) 6oz	104	5.9	5.5	7.9	206	.085
Yogurt (Greek) 6oz	198	6.1	16.4	7.3	225	.081
Cheese (whole) 1oz	115	6.5	9.4	.88	201	.17
Cow's Milk (whole) 8oz	149	7.7	7.9	11.7	276	3.1
Soy Milk (sw/fort) 8oz	104	6.3	3.6	12	299	2.6
Soy Milk (usw/fort) 8oz	74	7.8	3.8	3.6	300	3.0
Almond Milk (sw/fort) 8oz	56	1.0	2.5	8.1	450	2.5
Coconut Milk (uns/fort) 8oz	43	.47	4.5	.87	100	3.0

# Easy Ways to Measure out Extra Calories



# Techniques to Increase Calorie Intake

- Limit your intake of non-caloric foods and beverages (coffee, tea, water) These have no calorie benefit
- Capitalize on the times you have an appetite and add a few extra bites
- Try not to skip any meals
- Consume small frequent meals, every 2-3 hours throughout the day
- Try drinking some of your calories (whole milk, 100% fruit juice, a smoothie, meal replacement formula)



# Adding Calories Without Adding Too Much Volume

- Add regular sour cream or plain whole fat Greek yogurt as a topping to baked potatoes or casseroles
- Sprinkle chopped or ground nuts and seeds on cereals, salads, yogurt, or into smoothies
- Add a scoop of nut butter and/or dried fruit or syrup to oatmeal
- Always choose regular mayo, salad dressings, cream cheese, etc. Avoid diet or low fat products

# Adding Calories Without Adding Too Much Volume

- Add a TB of ground flax seeds, chia seeds or wheat germ to recipes for increased calories, healthy fats and fiber
- Add dried milk powder into milk, smoothies, or soups for added protein and calories
- Add sliced avocado to sandwiches or salads for a creamy texture and additional calories

# 250 Calorie Snack Ideas

- 2 oz cheese (any kind) and crackers
- Oatmeal/whole milk/honey/fruit
- Mini bagel with peanut butter
- Yogurt/berries/granola (look for whole milk yogurt)
- Hot chocolate with whole milk and whipped cream
- Tortilla chips and guacamole (100 Calorie servings available)
- Whole wheat crackers, nut butter and fresh apple
- Prepackaged peanut butter and crackers
- Prepackaged granola bar (any kind you like) and Juice



Food Item	Food Group Category	Calories	Changes	Calories
Instant Oatmeal Prepared with <del>Water</del> (1 packet)	G	165	Whole milk	315
<del>Low Fat Milk</del> (4oz)	D	50	Whole milk	75
Wheat Toast (1slice) with <del>Jelly</del> (1 tsp)	G/O	85	Butter or Marg	100
Orange Juice (8oz)	F	110		110
Tuna Sandwich (1/2 can, <del>water packed</del> ) w/mayo/lettuce/tomato slices	G/P/O/V	340	Oil packed	410
Fresh Banana	F	75		75
<del>Low Fat Milk</del> (8oz)	D	100	Whole milk	150
Grilled Chicken Breast (3oz)	P	145		145
Baked Potato (medium) with butter (1 tsp)	G/O	150		150
Steamed mixed vegetables (1.5 cup)	V	85		85
<del>Chocolate Ice Cream</del> (1 cup)	D	285	Premium brand	500
<del>Low Fat Yogurt</del> (6oz) and Berries (3/4 cup)	D/F	210	Greek yogurt	250
Supplement (240 calories)			added	240
Total Calories		1800		2605

# Adding Calories with Smoothies or Liquid Supplements



# Constructing a Smoothie

- Begin with Colorful Fruits and Vegetables
  - Peeled (apples, pears, peaches, banana, mango)
  - Berries (any kind) fresh, frozen, dried, canned
  - Greens (kale, spinach, arugula, collard, mustard)
  - Herbs & Spices (cinnamon, ginger, cloves, turmeric, cocoa)
  - Fruit Juices or Nectars

Choose Color



# Boosting Calories in a Smoothie

- Liquid Base (choose a high calorie base)
  - Milk (choose any type – cows, soy, almond, coconut, etc)
  - Supplement such as Boost or Ensure
- Add Protein
  - Whey or plant based protein powder
  - Silken Tofu, or soft cheese (cottage or mascarpone)
  - Nut butters (almond, peanut, etc.)
  - Powdered milk
  - Whole milk, or Greek yogurt



# Boosting Calories in a Smoothie

- Additional Calories and Fiber.
  - Seeds (flax, chia, etc)
  - Nuts or nut butters (almonds, walnuts, pecan, etc)
  - Avocado –adds a creamy texture
  - Oils (olive, canola, coconut, etc)
  - Ice cream, heavy cream





# Blueberry Avocado Smoothie

- 1 cup blueberries
- 1/2 avocado
- 1/2 cup apple juice (or any 100% fruit juice)
- 1/2 cup whole milk (any kind)
- 6 oz regular vanilla yogurt
- 1 TB flaxseed
- Recipe = 550 calories



# Techniques to Increase Calorie Intake

- Oral Supplements are a convenient source of calories/protein
- Some of these may also be used as tube feedings

■ Ensure Original (8oz)	220 calories
■ Boost Original (8oz)	240 calories
■ Carnation Breakfast Drink (8oz)	240 calories
■ Fibersource HN (8.45oz)	300 calories
■ Ensure Plus (8oz)	350 calories
■ Isosource 1.5 (8.45oz)	375 calories
■ Resource 2.0 (8oz)	480 calories

- <https://www.nestlehealthscience.us/brands>
- <http://www.abbott.com/our-products.html>



# What About Other Supplements?

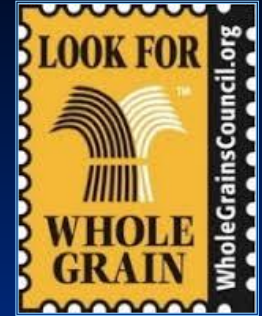
- There are many supplements on the market (vitamin, mineral, herbal, amino acid, etc.)
- Packaging can be confusing and/or misleading
- Manufacturers of supplements do not have to provide the FDA with data that demonstrate the safety or purity of their products prior to marketing
- Many supplements interact with medications, using the same metabolic pathways and may interfere with absorption.
- Ask your Physician, Nurse or Dietitian prior to use

# Symptom Management

## ■ Exhaustion

- Try to nap before meals
- Eat soft foods that involve less chewing
- Cut your food into small pieces
- Substitute a high calorie supplement for all or part of a meal
- Choose from all foods groups for more balanced meals
- Consume small, more frequent meals (6 per day). Try smaller portions at mealtimes and nutritious snacks between meals and in the evening
- Avoid foods that require lengthy chewing like steak and salad
- Use your feeding tube to supplement your intake

# Symptom Management



## ■ Constipation

Constipation can be helped by eating a diet high in fiber and by drinking lots of fluids. Fiber and fluid work together to make the stool soft and to keep your bowel movements regular

## ■ Foods that contain Fiber

- Whole grain and whole wheat products, such as breads, cereals, pasta, brown rice, oats, barley and quinoa
- Legumes such as cooked dried peas, beans, and lentils
- Seeds, such as flax, and chia. Nuts
- Vegetables and fruits, including dried
- Supplements that contain fiber (Fibersource, Jevity)

# Symptom Management



## ■ Dehydration

- Water is the best to rehydrate your body,  
but fruit juices, milk and broth are all good choices
- Eat foods with high water content. Liquid in your solid food counts towards your daily total. Choose fruits, vegetables, soups, stews, popsicles, water ice and gelatins
- Fluid Needs = 1cc per calorie (rule of thumb)
- $2600 \text{ calories} = 2600\text{cc} / 30\text{cc} = 86.6 \text{ oz} / 8 \text{ oz} = 10.8 \text{ cups}$ 
  - (30cc per fluid ounce)

# Symptom Management



## ■ Swallowing

- Diets with modified textures are a key strategy for people who have difficulty chewing or swallowing
- Work with your Speech-Language Pathologist to determine the appropriate food texture and beverage thickness, then your dietitian for diet/food suggestions
- It is very important to continue to consume a variety of foods and to maintain intake of liquids while following a modified texture diet
- Modified texture diets change throughout the progression of ALS – reevaluate your needs often !

# Symptom Management

## ■ Excess Saliva Production

- Remember to swallow frequently, but slowly and carefully
- Foods that are very sweet or very sour may stimulate salivation
- Stay well hydrated
- If you feel that milk thickens your saliva, try soy substitutes for milk, ice cream, and yogurt in drinks and cereal
- You may be better able to tolerate foods with “cooked” milk such as pudding and custard
- Eat foods with higher water content such as canned fruits, well cooked vegetables, yogurt, custard and pudding.



# Key Points

- Evaluate and re-evaluate nutritional status often – use your team!
  - Weight / BMI
  - Calorie needs change throughout the progression of ALS
  - Swallowing
  - Breathing
  - Calorie Needs / Calorie Intake / Fluid Intake
  - Symptoms
- Consider a feeding tube early
  - When ALS interferes with the ability to swallow food and fluids
  - When nutrition needs cannot be met by eating
  - Before significant weight loss
  - Before breathing is severely impaired

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