

WELCOME!

March 20, 2023



Nutritional Considerations in ALS

Guest Speaker:

Michelle McDonagh, RD, CD
Outpatient Dietitian-ALS, CF, and Diabetes Care Clinics
The Medical College of Wisconsin & Froedtert Hospital

ALS Association

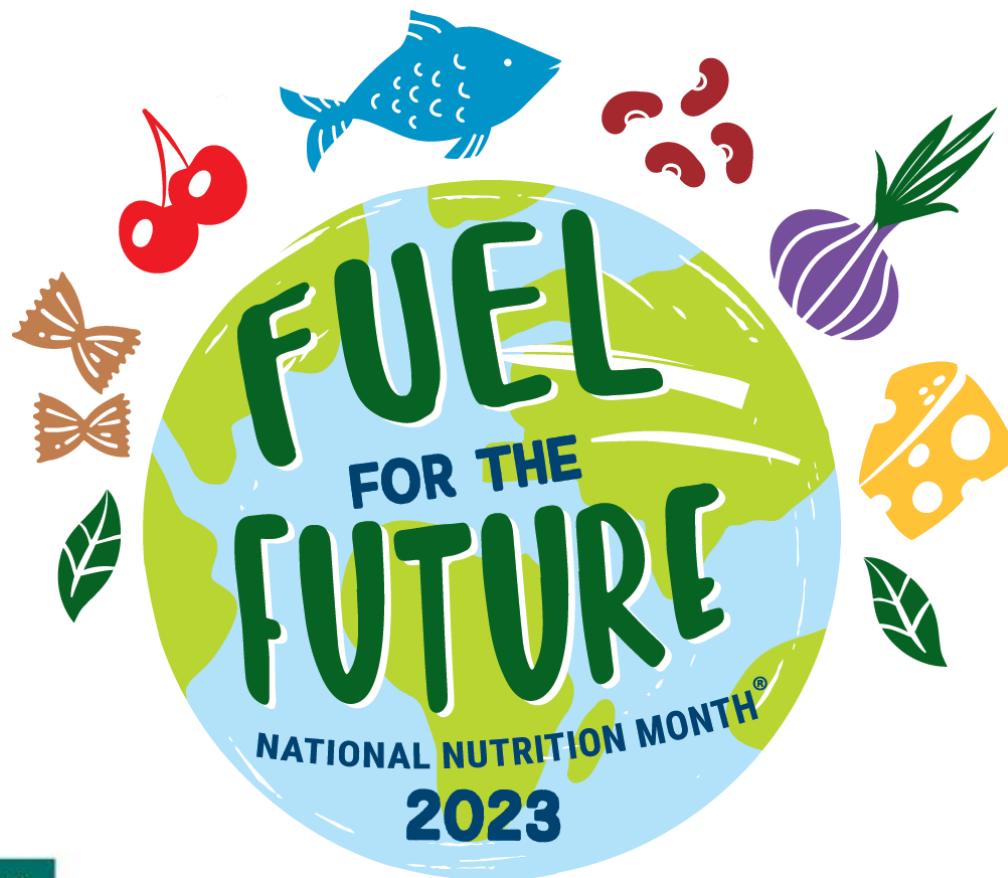
National Office-Care Services

Ph: 800-782-4747 Cynthia.Knoche@als.org

Nutritional Considerations in ALS

Michelle McDonagh, RD, CD
Froedtert & MCW, Milwaukee, Wisconsin

Happy National Nutrition Month!



Why is Food so Important?

- Social
- Emotional
- Culture
- Religion
- Physical



Why is Nutrition Important in ALS?

- Nutrition: independent risk factor for disease progression
 - Calories are needed to maintain weight. Resting energy expenditure known to be higher in ALS.
 - Association between body mass index (BMI) and ALS survival, with $BMI < 18.5$ associated with shorter survival
 - BMI 30-35 associated with slower progression, longer survival



Why is Nutrition Important in ALS?

- Adequate nutrition necessary to maintain highest possible level of function
- Improved endurance
- Protect body from infection and illness
- Preserve enjoyment of food and maintain socialization



ALS COSMOS Study

- Amyotrophic Lateral Sclerosis Multicenter Cohort Study of Oxidative Stress
- 302 patients
- Modified Block Food Frequency Questionnaire,
- Function was measured using the ALS Functional Rating Scale–Revised (ALSFRS-R)
- Respiratory function was measured using percentage of predicted forced vital capacity (FVC).

ALS COSMOS

- Macronutrient intake did not impact ALSFRS-R score or percent FVC
- Milk was negatively associated with ALSFRS-R and FVC BUT milk based supplements slowed functional decline/stabilized weight in another study. *
- Regression analysis of “good food groups” showed that eggs, fish, poultry, nuts and seeds, beneficial oils, fruits and vegetables in general were positively associated with ALSFRS-R scores and percent FVC.



[*Silva LB, Mourao LF, Silva AA, et al. Effect of nutritional supplementation with milk whey proteins in amyotrophic lateral sclerosis patients. Arq Neuropsiquiatr. 2010;68\(2\):263-268.](#)

ALS COSMOS

- Good micronutrient intake was positively associated with ALSFRS-R scores and percent FVC.
- Key micronutrients:
 - Carotenes- carrots, pumpkin, sweet potato, broccoli, spinach
 - Lycopene-strong antioxidant properties. It's the pigment in red and pink fruits, such as tomatoes, watermelons and pink grapefruit.
 - Fiber from vegetables and grains.



ALS COSMOS

- Omega-3 fatty acids-oily fish, tuna, mackerel, herring, nuts and seeds (walnuts, chia seeds, flaxseeds), oils (flaxseed oil, canola oil) and fortified eggs, milk, soy milks.
- Omega-6 fatty acids-soybean, corn, safflower, sunflower oil, nuts, seeds, meat poultry, fish, eggs.
- Isoflavones- **Soy** and its products, and legume seeds (lentils, beans, peas) are the richest sources. Exhibit antioxidant, anticancer, antimicrobial, anti-inflammatory properties



High Calorie Diet

- Resting energy expenditure known to be higher in ALS.
- A randomized multicenter trial of pALS with feeding tubes found that high carb, high calorie diet was better tolerated/better outcomes than standard calorie diet (control) or high fat, high calorie diet.

Willis AM, Hubbard J, Macklin EA, Glass J, Tandan R, Simpson EP, Brooks B, Gelinas D, Mitsumoto H, Mozaffar T et al.
Hypercaloric enteral nutrition in patients with amyotrophic lateral sclerosis: a randomised, double-blind, placebo-controlled phase 2 trial. Lancet 2014; 383:2065-2072.
<https://pubmed.ncbi.nlm.nih.gov/24582471/>

Fat calories can be Fab calories

- Protein – 4 kcal/g. Important to help maintain muscle mass.
- Carbohydrate – 4 kcal/g. Major source of energy in the average diet.
- Fat-9 kcal/g. Most calorie-dense nutrient. Increased circulating cholesterol may have neuro-protective benefits.
- Kasarskis equation [Maintaining Adequate Nutrition: A Continuing Challenge in ALS | The ALS Association](#)
- My Data Helps app, search for ALS Nutrition

Calorie-Dense Foods

- Add calories without volume with butter, cheese, gravy, cream, mayo, peanut butter, dressing, dips
- Whole fat dairy
- Ice-cream –yum!
- Casseroles
- Calorie containing beverages
- “Healthy”- olive oil, olives, nuts, nut butters, seeds, avocado, dried fruit



Fatigue and Poor Appetite

- Six small meals-reduce fatigue at meals and fuel body throughout the day
- Select foods that are easy to chew and swallow
- Drink supplements between meals
- Eat your favorite foods
- Cook aromatic foods/presentation/company
- Select calorie-dense foods

Food Preparation

- Occupational therapist recommends assistive devices/feeding assistance for those with UE weakness.
- Convenience meals
- Batch cook meals and freeze single serving portions
- Caregivers setting up snacks/beverages where they are accessible
- Meals on wheels



Protein Foods

- Protein is an important component of muscle and other body tissues.
- Protein requirements 1.2-1.5 g/kg
 - Meat
 - Fish
 - Eggs
 - Dairy (cottage cheese, greek yogurt, milk)
 - Nuts and nut butters
 - Seeds
 - Beans
 - Protein powder/shakes



Oral Nutrition supplements

- Ensure / Equate / Boost PLUS has 100 extra calories per serving
- Carnation Instant Breakfast
- Kate Farms / Orgain
- Ensure Clear (juice)
- Lutrish shakes
- Benecalorie
- Homemade shakes



Brain Power Smoothie

- Ingredients:
- 2 cups blueberries
- 1 cup pomegranate juice (or any berry juice)
- 1 cup ice cubes
- 1 Tbsp. chia seeds
- 1 ripe banana, peeled
- half of an avocado, peeled and pitted
- <http://www.gimmesomeoven.com/brain-power-smoothie-blueberry-avocado-smoothie-recipe/>
- Nutrition: 620 calories, 8 g protein, 20 g fat, 117 g carbohydrate, 22 g fiber

Dysphagia

- Coughing and/or choking on food or liquid while swallowing
- A wet or gurgling-sounding voice immediately after swallowing food or liquid
- Difficulty chewing
- Food escaping out of the mouth during chewing or liquid spilling from the lips
- Prolonged mealtimes
- The need for smaller bites and/or sips
- Difficulty managing saliva
- Shortness of breath during meals

Ways to Manage Dysphagia

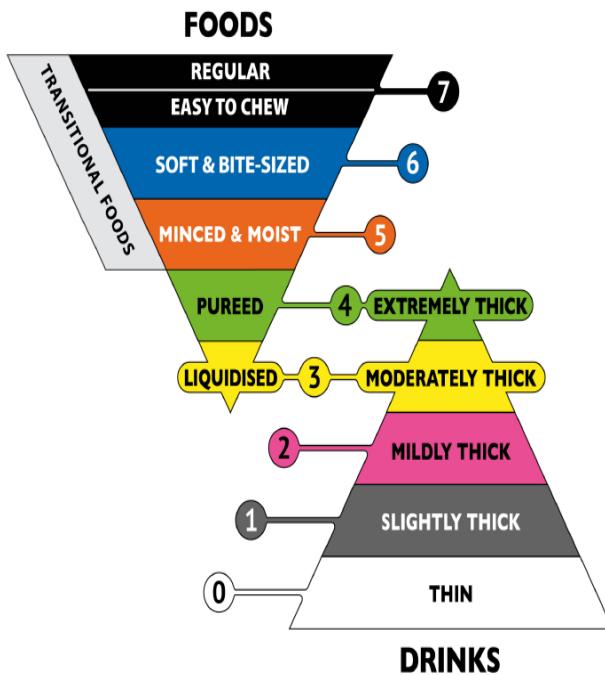
- Swallow strategies under guidance of the Speech Therapist, Video Swallow Study
- Diet modification
- Dietary supplements
- Feeding tube placement



Diet Modification

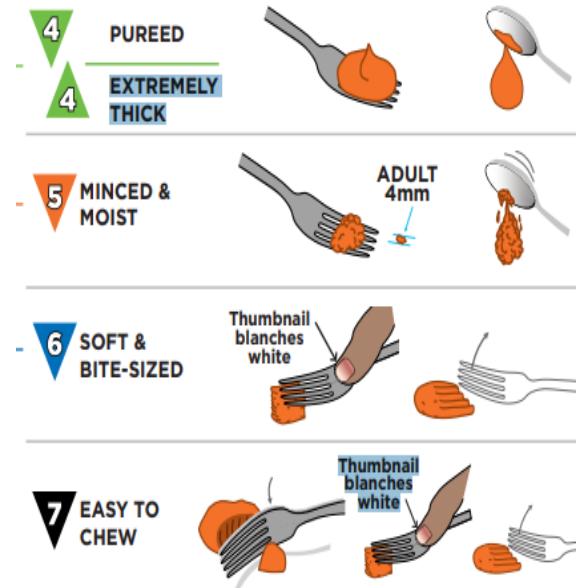
Diet Level	Examples of Food
Level 1: Pureed	Pudding, pureed oatmeal, bread, meats, hummus, pureed fruit and vegetables
Level 2: Mechanical Soft	Scrambled eggs, meatloaf, well-cooked vegetables, pancakes, mashed potatoes, canned/cooked fruit
Level 3: Advanced	Bread slices, muffins, pasta, casseroles, baked potatoes, soft/ripe fruits, fish
Level 4: Regular	No food avoidances or restrictions
Nectar Thickened Liquids	Slightly thicker than water
Honey Thickened Liquids	Consistency of honey at room temperature

Diet Modification



Copyright: The International Dysphagia Diet Standardisation Initiative 2016
@ <https://iddsi.org/framework/>

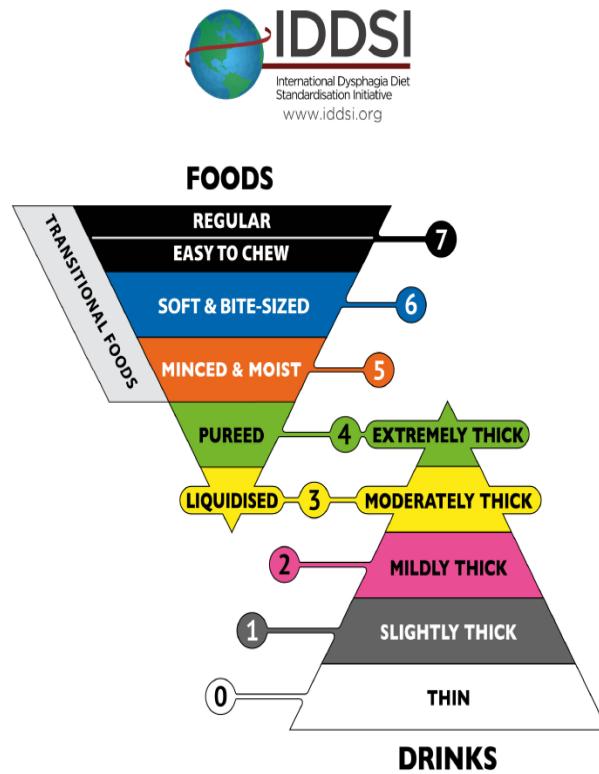
FOOD TEST INSTRUCTIONS



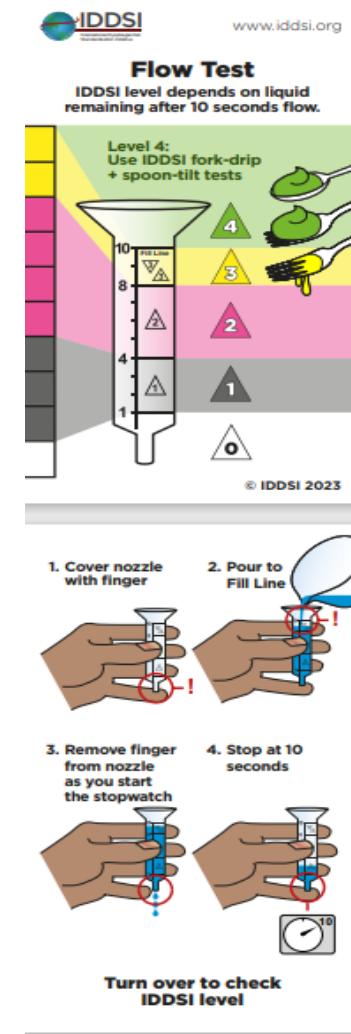
Diet Modification



www.iddsi.org



Copyright: The International Dysphagia Diet Standardisation Initiative 2016
@ <https://iddsi.org/framework/>



Regular Diet

- Sample Menu provides:
 - 1700 calories, 82 g protein, 25 g fiber
 - 20% of calories as protein
 - 53% of calories as carbohydrate
 - 27% of calories as fat

Breakfast

1 egg
1 cup bran cereal
1 cup skim milk
5 prunes

Lunch

4 oz salmon
1 cup brown rice
1 cup broccoli

Dinner

2 oz deli turkey
1 oz cheddar cheese
1 slice wholegrain bread
Side garden salad (1.5 cups)
1 T Italian dressing
1 cup grapes

Snacks

1 medium apple
1 low fat yogurt

Beverages

34 oz Water
8 oz coffee with 2 oz skim milk

Pureed Diet

- Sample Menu provides:
 - 1750 calories, 85 g protein, 15 g fiber
 - 20% of calories as protein
 - 53% of calories as carbohydrate
 - 27% of calories as fat
- Note ↓ dietary fiber and ↑ saturated fat intake increased in order to meet calorie needs

Breakfast

1 egg pureed with 0.5 oz cheese
1 cup cream of wheat with 8 oz whole milk and cinnamon
6 oz prune juice

Lunch

3 oz salmon pureed
1/2 cup pureed rice with ¼ cup chicken broth
1/2 cup broccoli pureed with 1 tsp olive oil

Dinner

1 cup canned mashed sweet potato with 2 T butter and 1 T brown sugar

Snacks

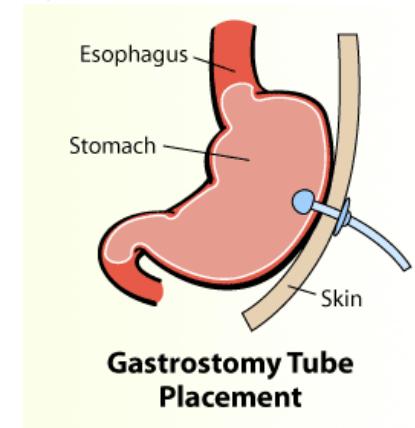
1 cup Cottage cheese with ½ cup peaches and ½ cup fruit juice pureed

Beverages

34 oz Thickened (Nectar Thick) Water
6 oz coffee with 2 oz whole milk (Nectar thick)
Ensure Plus (350 kcal, 13 g protein)

Feeding Tube

- Indications for feeding tube placement:
 - Weight loss
 - Chewing/swallowing difficulties –Eating has become a burden
 - Prolonged mealtimes
 - Fatigue after meals
 - No appetite/no interest in food
 - Decline in respiratory function
- Maintain/supplement nutrition, hydration, alternate route for medications.



Benefits

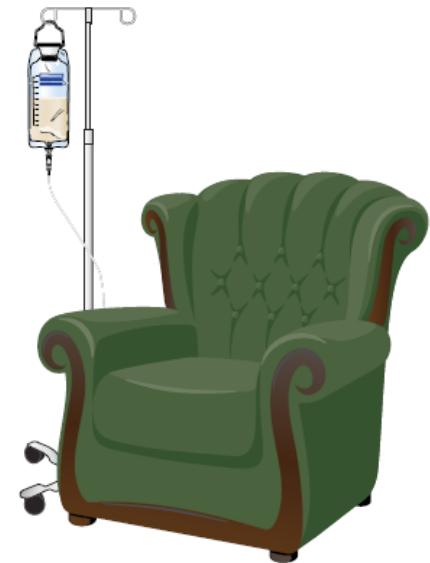
- Promotes adequate intake of:
 - Calories, protein & fluid
 - Weight stabilization
 - It does not prevent eating by mouth
- Decreased risk of aspiration
 - No choking, chewing & swallowing problems
- Improve quality of life
- Easy medication administration
- Feeding times=simple, shorter
 - Energy saved for other activities

Things to Consider....

- Placement
 - Sedation necessary
 - Infection risk
- After placement
 - Clogging may occur
 - Infection at feeding tube site
 - Replacement of tube
 - Daily care
 - Intolerance to tube feeding formula-work with your Dietitian!

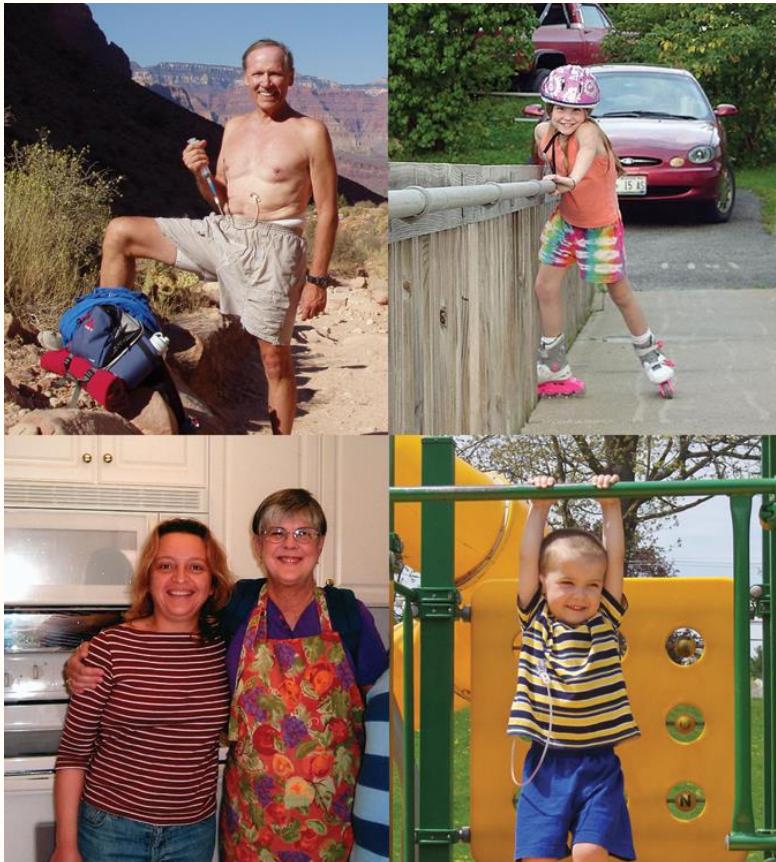
How is it used?

- Syringe feeding
 - Gravity feeding (IV pole and bags)
 - Pump assisted feedings.
-
- Orders generally through DME provider.
 - Insurance coverage varies.



Tell Your Patients About

The Oley Foundation



- FREE information and support for patients on home tube or IV feedings
- www.oley.org
- (800) 776-OLEY
- www.feedingtubewarneness.org
- [FYI: Information About Feeding Tubes | The ALS Association](http://FYI.Information>About.Feeding.Tubes.The.ALS.Association)

Hydration

- Multicenter trial (Sgagnelli et al, 2018) assessing hydration found that survival was two-fold longer in the group above the median for estimated water intake. Regardless of nutrition, hydration is an independent risk factor for survival.
- Increased risk -dysphagia, limited mobility, female
- Monitor urine concentration, bowel function
- Eat foods with a high water content e.g. canned and fresh fruit/ vegetables, drinkable yogurt, pudding, juice, purees, cream soups, smoothies, nectars
- Straw, long straw, nosey cup



[Full article: Hydration measured by doubly labeled water in ALS and its effects on survival \(tandfonline.com\)](#)

Constipation

- Dehydration, inactivity, weakened abdominal muscles, insufficient fiber intake
- Increase fiber –fruit, vegetables, whole grains
- Increase fluids
- Prune Juice
- Laxatives and stool softeners

Move It!

- 1 Cup Unprocessed Bran (Store in freezer)
- 1 Cup Apple Sauce
- $\frac{1}{2}$ Cup Prune Juice
- Mix together well-store in refrigerator (1-2 tablespoons per day – adjust as necessary)

Vitamin Supplements

- Vitamin D –study showed association between low levels and ALS. Screening for deficiency*.
 - Multi-vitamin with minerals for general health. Should have the approval of US Pharmacopeial Convention
 - Coconut Oil
 - www.ALSuntangled.com
- * Camu W, Tremblier B, Plassot C, Alphandery S, Salsac C, Pageot N, Juntas-Morales R, Scamps F, Daures JP, Raoul C. Vitamin D confers protection to motoneurons and is a prognostic factor of amyotrophic lateral sclerosis. *Neurobiol Aging*. 2014 May;35(5):1198-205. doi: 10.1016/j.neurobiolaging.2013.11.005. Epub 2013 Nov 13. PMID: 24378089.



Resources

- Bouteloup C, Desport JC, Clavelou P, et al. Hypermetabolism in ALS patients: an early and persistent phenomenon. *J Neurol.* 2009;256:1,236-t242.
- Körner, S., Hendricks, M., Kollewe, K. et al. Weight loss, dysphagia and supplement intake in patients with amyotrophic lateral sclerosis (ALS): impact on quality of life and therapeutic options. *BMC Neurol* 13, 84 (2013). <https://doi.org/10.1186/1471-2377-13-84>
- Kasarskis EJ, Mendiondo MS, Matthews DE, Mitsumoto H, Tandan R, Simmons Z, Bromberg MB, Kryscio RJ; ALS Nutrition/NIPPV Study Group. Estimating daily energy expenditure in individuals with amyotrophic lateral sclerosis. Am J Clin Nutr. 2014 Apr;99(4):792-803. doi: 10.3945/ajcn.113.069997. Epub 2014 Feb 12. PMID: 24522445; PMCID: PMC3953880.

Resources

- Desport JC, Preux PM, Truong TC, Vallat JM, Sautereau D, Couratier P. Nutritional status is a prognostic factor for survival in ALS patients. *Neurology* 1999; 53:1059-1063.
- Connor N. Scagnelli, Diantha B. Howard, Mark B. Bromberg, Edward J. Kasarskis, Dwight E. Matthews, Hiroshi M. Mitsumoto, Zachary Simmons, Rup Tandan & for the ALS Nutrition-NIPPV Study Group (2018) Hydration measured by doubly labeled water in ALS and its effects on survival, *Amyotrophic Lateral Sclerosis and Frontotemporal Degeneration*, 19:3-4, 220-231, DOI: [10.1080/21678421.2017.1413117](https://doi.org/10.1080/21678421.2017.1413117)