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ALS Advocacy: Enormous Win Ending SSDI Waiting Period

The ALS community earned a hard-fought victory in December with passage of the ALS Disability Insurance Access Act, ending the five-month waiting period for people with ALS to start receiving their Social Security Disability Insurance (SSDI) benefits. The ALS Association has been tirelessly engaged in building support for this policy in Congress from day one, developing the bill with congressional champions and working with ALS advocates over the years to introduce the bill and lay the groundwork for this win.

Since the legislation was first introduced in 2016, ALS advocates have reached out to members of Congress more than 54,000 times through phone calls, letters, in-person meetings, and via social media. This campaign to educate lawmakers and the public about the rapid progression of ALS and the long delays in diagnosis contributed to a steady increase in support for the legislation. People living with ALS do not have five months to wait for SSDI benefits they have worked for over the course of their careers.

When legislation to waive the five-month waiting period was first introduced, it had just a single sponsor in the House of Representatives. Thanks to the hard work and determination of advocates everywhere, the bill gained 20 Senate cosponsors and 55 House cosponsors by the end of 2016. When a new Congress convened the following year, the bill was reintroduced with 33 original cosponsors in the House and Senate. ALS advocates continued to work, educating lawmakers and building momentum to the point where 67 Senators and 305 members of the House supported the bill just two years later in 2020.

“A bill can look like it was easy to get done when it passes 96-1, but that doesn’t mean that the pathway was easy. This has been years, and years of effort,” said Sen. Sheldon Whitehouse (D-R.I.) after the Senate voted to pass the bill he cosponsored. In the four years since this bill was first introduced, less than 3% of all bills have passed into law.

The ALS Association is incredibly grateful for all of the ALS advocates, partners, and ALS organizations around the country who joined us in the fight to make this landmark legislation a reality. The passage of this bill shows the ALS community that their voices are truly being heard.

Support Groups

The ALS Association Mid-America Chapter has suspended all in-person support groups at this time, for the protection of the ALS community and our staff.

The Chapter does have teleconference support groups that you can participate in by phone and/or Zoom technology.

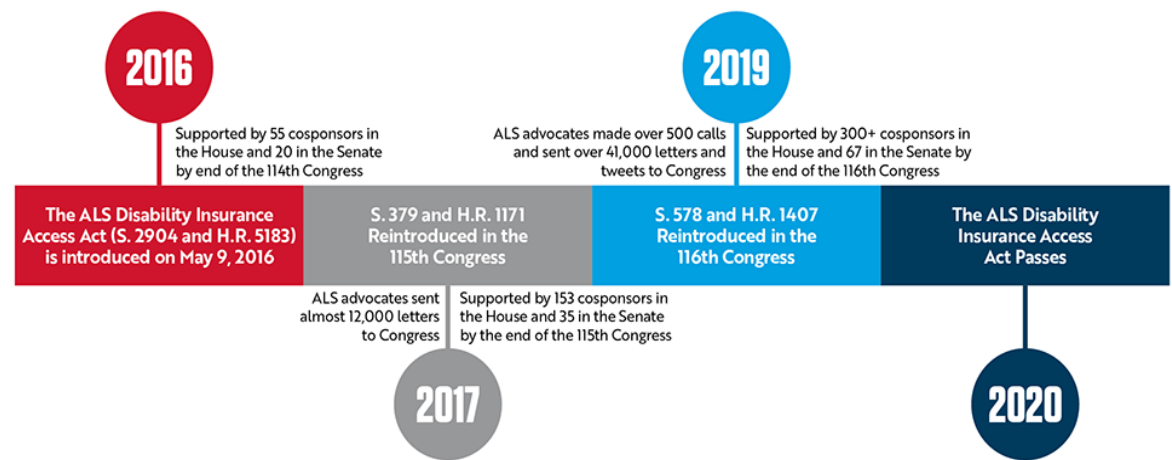
Caregivers

Support Group
Tuesday, January 12th
2 p.m.
Contact Cheri Mathis at cmathis@alsa-midamerica.org to sign up for instructions to join this meeting or call (800) 878-2062 for more information.
Meets the second Tuesday of the month.

Support Group
(People living with ALS, Caregivers and Survivors)
Monday, January 18th
4:30 p.m.
Contact Kim Harber at kharber@alsa-midamerica.org to sign up for instructions to join this meeting or call (800) 878-2062 for more information.
Meets the third Monday of the month.



Timeline of The ALS Disability Insurance Access Act



Quality of Life Grant Program

The ALS Association Mid-America Chapter’s Quality of Life Grant program assists with the care and needs of those living with ALS in Kansas, Missouri and Nebraska. The \$400 grant reimburses ALS families for their needs in respite, communication, home modification, access to medical care and for special circumstances.

The Quality of Life Grant will provide a maximum benefit of \$400 annually to a person living with ALS in Kansas, Nebraska or Missouri

Below are some of the ways the grants are being used:

- 1) Respite:** professional home care, Patient Care Sitter (cannot be a resident of the home), house cleaning services, lawn and yard care/snow removal.
- 2) Communication:** communication device, computer software or apps for communication, alert devices, and adaptive switches for tablets or computers.
- 3) Home Modification:** building of ramps (material & labor), bathroom accessibility (material & labor), doorway accessibility (material & labor), and grab bar accessibility (material & labor).
- 4) Access to ALS Clinic and/or hospitalization:** mileage to and from ALS clinic and/or hospital, rental of vehicle and/or car services to get to and from ALS clinic and/or hospital, lodging for ALS clinic and/or hospital (1 room, 2-night limit), and incidentals for ALS clinic and/ or hospital (i.e. tolls, parking fees, meals).

If you are interested in this program, please contact your local ALS Navigator and they will send you the link to the online application form to complete. Or if you prefer, your local ALS Navigator can mail you a physical copy of the application.

High Calorie and Easy to Chew Recipes

Once ALS takes away a person’s ability to swallow safely, maintaining adequate nutrition can become a challenge for people living with ALS and their caregivers.

For people living with ALS, it is important to ensure that a meal is not only nutritional and tasty, but also easy to swallow. To help maintain a healthy and nutritious diet, there are many tactics to consider as you plan your meals. For example, choose foods that are normally soft that require little chewing, such as bread, rice, pudding, hummus, soft boiled eggs, and apple sauce. “Lubricating” foods can make it easier to swallow dry foods using sauces, gravies, dips, and dressings, all of which are often plentiful with holiday recipes.

Modifying the consistency of food using a blender or food processor can help make foods easier to chew and swallow, turning them into a pleasantly thick liquid by blending with water, milk, almond milk, or soup.

While adjusting to a “new normal” of eating with ALS can take a little creativity at times, there are many delicious and healthy recipes to consider. Below are a few high calorie and easy to chew recipes.

<div><div><div><div><div><div></div><div>Breakfast Burrito</div></div></div><div><div>Ingredients:</div><div><ul style="list-style-type: none">1 flour tortilla1 can beans1 dollop of sour cream1 tablespoon salsa1/4 cup shredded Monterey Jack or cheddar cheese2 eggs1 splash whole milk</div></div><div><div>Directions:</div><div><ol style="list-style-type: none">Spread the center of the tortilla with 1 Tbsp drained and rinsed canned beans mashed to a paste with a little sour cream.Sprinkle it with a Tbsp of salsa and ¼ cup of shredded Monterey Jack or cheddar cheese.Scramble 2 eggs (using a splash of whole milk) and spoon them across the center of the tortilla.Roll up the burrito, tucking in the ends.Heat it in the microwave for about 20 seconds, just long enough to melt the cheese. Serving size: 1</div></div></div></div></div>	<div><div><div><div><div><div></div><div>Mom’s Meatloaf</div></div></div><div><div>Ingredients:</div><div><ul style="list-style-type: none">1 pound ground beef3/4 -1 cup plain fine bread crumbs3 tablespoons dried onion flakes1 teaspoon salt1 heaping teaspoon dried parsley1/4 teaspoon black pepper1/8 teaspoon poultry seasoning1/8 cup ketchup1 eggMilk</div></div><div><div>Directions:</div><div><ol style="list-style-type: none">Mix ground beef and bread crumbs in large bowl.Mix seasonings, ketchup, and egg into beef and crumb mixture.Add enough milk to bind it all together and mix until smooth consistency.Spray loaf pan with cooking sprayPut meat mixture in loaf pan.Bake at 350 degrees for about 45 minutes or until cooked through.</div></div></div></div></div>
<div><div><div><div><div><div></div><div>Chilled Avocado Cucumber Soup</div></div></div><div><div>Ingredients:</div><div><ul style="list-style-type: none">1/2 medium cucumber1 ripe small avocado1 scallion1 garlic clove2 tablespoons fresh lemon juice1/2 cup plain yogurt1/2 cup cold water1/2 cup ice cubes</div></div><div><div>Directions:</div><div><ol style="list-style-type: none">Peel cucumber and cut into 4 pieces. Quarter avocado, removing pit, and peel. Cut scallion into large pieces.In a blender puree all ingredients until smooth and season with salt and pepper. Serving size: 2</div></div></div></div></div>	<div><div><div><div><div><div></div><div>Strawberry Cheesecake Quesadillas</div></div></div><div><div>Ingredients:</div><div><ul style="list-style-type: none">4 (8 inch) flour tortilla2 tablespoons softened cream cheese2 tablespoons strawberry jam1 tablespoon confectioners’ sugar</div></div><div><div>Directions:</div><div><ol style="list-style-type: none">Spread one side of 2 tortillas with 1/2 the cream cheese. Spread equal amounts jam over cream cheese. Spread remaining 2 tortillas with remaining cream cheese, and place on top of first 2 tortillas to form quesadillas.Place quesadillas in a skillet sprayed with cooking spray over medium heat and cook 5 minutes on each side, until golden brown.Serve sprinkled with confectioners’ sugar.</div></div></div></div></div>