

Chopping our Way Through the Holiday

It's cold outside and the best holiday gatherings have just begun! This season we are continuing our series on must-have adaptable kitchen gadgets and since it's a busy time in the kitchen for all of us, I thought we can discuss tools for kitchen preparation.

As an adult with Spina Bifida, cooking at home can be quite an exhausting experience and helping in the kitchen during the holidays is the last thing I want to think about lately. However, I found two kitchen accessories I have been able to use regularly, cutting my cooking time down, all while making me look like a speedy sous-chef to my distant relatives cooking during the holiday. A vegetable chopper and garlic press has made it extremely easy to do quite difficult knife work. This holiday, I decided to wow my family by making homemade stuffing using my vegetable chopper and garlic press for prepping while baking the stuffing in my rice cooker!! It was so easy,



yet it looked like I slaved in the kitchen for hours! Page 5 contains the recipe I used and special tips for shopping and safety use!
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A Winter of Self-Discovery

Winter can be a time of self-discovery. Albert Camus, a philosopher, author, and Nobel Prize winner, once wrote, "In the depth of winter I finally learned that there was in me an invincible summer." This issue of our newsletter is meant to help you discover new things about yourself and your skills. We challenge you to add flavor to your meals with unfamiliar herbs and spices, experiment with a new kitchen gadget, measure your progress with exercise, get creative with adaptive fashion, and advocate for yourself and others. We hope that a moment spent discovering something new will stick with you for many seasons to come.

Written by Brad Dicianno, MD

Advocacy is Essential

As kids our parents advocate for us to schools, doctors, and insurance companies. As adults we take over and advocate for ourselves to all those same people plus employers. But did you know that you can advocate for more than just yourself? Our state and federal governments are the ones who make the policies that affect our lives. From healthcare to employment to the ADA, our representatives make decisions that impact us. Most of the time the representatives in the Commonwealth and in Congress do not know the first thing about Spina Bifida or what we need to live and to thrive. We can educate them through advocacy.

We can call or write legislators about our story. We can tell them what it is like to live with Spina Bifida. We can tell them what we need to live our best lives. We do not have to do this alone. The Spina Bifida Association's national office holds an event every year called Teal on the Hill. Since the pandemic it has been virtual. It will be held again from February 26th to the 28th, 2023. Don't worry if you have never done any kind of advocacy like this before. Training is provided by the SBA and other people with Spina Bifida who have been doing this work



for a while. It is the time to meet with others with Spina Bifida and the people who represent us. You get to tell your story. Letting legislators know who you are, how you live, your life and what you need, is one of the best ways to ensure funding and policy changes. Together we can have impact and improve the lives for everyone living with Spina Bifida. Click on this [link](#) for more information about Teal on the Hill.

Written by Monica Albert Still, RN, BSN

Open Up Pittsburgh

Open Up Pittsburgh Studio is a nonprofit organization in the heart of Pittsburgh's Lawrenceville neighborhood that focuses on mindfulness and movement for individuals of all ages and abilities. Open Up Pittsburgh's mission is



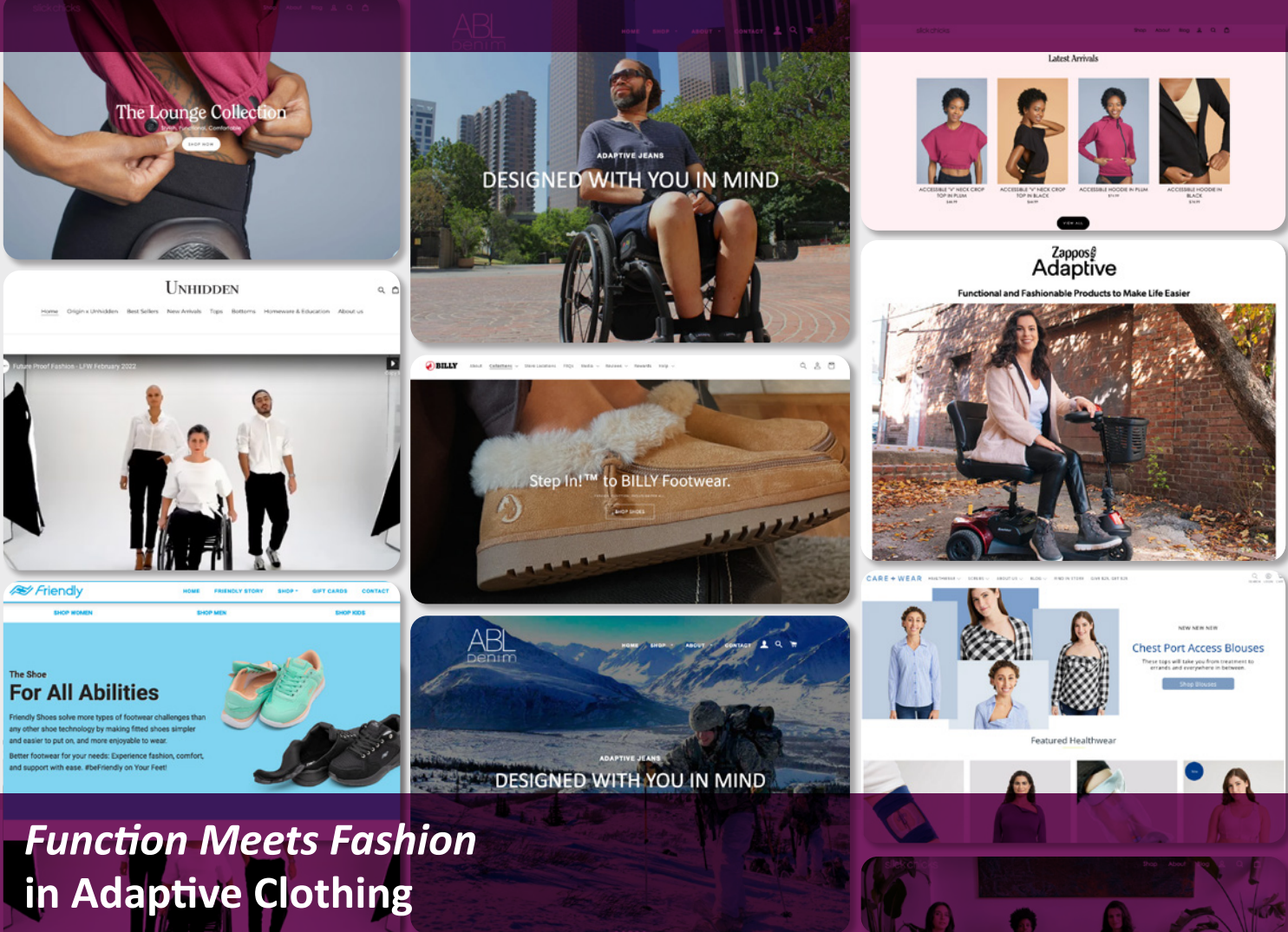
to teach mindfulness tools and movement practices, centering on individuals living with disabilities. Open Up Pittsburgh offers a variety of classes and activities which include dance, yoga, mindful

movement exercises, and so much more. Through participating in the inclusive, engaging, and fun activities that Open Up Pittsburgh offers, participants gain a deeper self-awareness, connection with their peers, and find creativity in self-expression. Their classes are very affordable and are specifically donation-based with 100% of the donations going towards the daily operations of the studio. You can learn more about Open Up Pittsburgh and sign up for classes and other activities by visiting Open Up Pittsburgh's website at: www.openuppittsburgh.com

Leadership, Empowerment, and Advocacy Fund (LEAF) Scholarships

The Pennsylvania Developmental Disabilities Council offers LEAF Scholarships which provide support for self-advocates and families to attend events that promote leadership, education, and self-advocacy, thereby enabling people with developmental disabilities and their family members to expand their knowledge and skills. The LEAF Scholarship program provides scholarships of up to \$750 per person, per year, to assist individuals with disabilities and their family members to attend conferences, training sessions, and comparable activities directly related to skill development in the areas of self-advocacy, leadership, and education. For more information visit this [website](#).

Written by Brad Dicianno, MD



Function Meets Fashion in Adaptive Clothing

What is important to you as you select your outfit for the day? Does a particular color make you feel good? Is comfort a priority? Does it not matter to you if it's clean? Maybe you don't feel like you have a choice; you must go with your limited options that work with your braces. Function is important but feeling good in what you wear is also important. Function is not always the priority when it comes to fashion (consider the high-heeled shoe for example!) but that doesn't mean appearance should be completely forgotten in accessible clothing. I did a bit of research to see what options there are out there for people who need adaptive fashion and found some interesting brands! Check these out!

Unhidden Clothing: The founder designs clothes with accessibility in mind. They offer trousers designed specially to allow for bloating, colostomy bags and ease of putting on, shirts with discreet tube access and keep wheelchair users in mind with all their designs.

Care+Wear makes highly functional health wear that creates positive and effective healing experiences for people everywhere.

Friendly Shoes: The brand offers adaptive footwear that includes Parkinson-friendly shoes, child-friendly slip-ons, and mid-tops with biomechanical zippers that are easy to throw on. They also accept returns and make donations to disabled veterans.

BILLY Footwear: In the founder's own words: "It became a mission to create mainstream shoes that are functional, fashionable, and inclusive for everyone." Billy offers shoes in many styles that work with braces such as AFOs. They even have some handsome looking dress shoes!

ABL Denim makes jeans for people with limited mobility or dexterity and sensory sensitivities. They can be purchased only through Zappos.

Slick Chicks makes adaptive underwear with clasps on both sides making it easy to dress while lying down or standing.

Zappos Adaptive is a major retailer with tons of adaptive shoes. They also allow you to buy a single shoe if you only need one!

Written by **Darcie Ilg, PA-C**



WHEELCHAIR WORKOUT



Track Your Gains,
Unlock Your Potential!



There are many ways to track your improvements during training. One of my favorite ways to track improvements in strength is using **Reps in Reserve (RIR)**. Reps in Reserve refers to a specific set, or a single round of reps, within your training session and how many more reps you think you could have done in that set after you finish the set.

RIR is measured by a scale of one to ten. Let's take pushups for example. If you do five pushups and feel like you are struggling on the last rep and your form starts to break down, but you get the rep to full extension with your elbows locked out at the top, and you are not able to complete another full rep with good form, then you would consider yourself to have zero reps in reserve for that set on that day. Now, let's say you do 10 pushups. You get to the last rep with great form, and you feel like you could 5 more reps. You would then consider yourself to have 5 reps in reserve for that set on that day.

This is a new but simple concept that can help you see improvements in your training, especially if you are tired or confused with having a set number of reps to hit or a certain percentage of your one rep max for a certain exercise that you usually must hit. Not every day is going to be your best day of training whether you miss a lift, or you just aren't feeling your best. RIR can help you stay on track and motivated by looking at that specific day's lifts and reps achieved and setting a goal for later training sessions to hit a higher goal. The key is to be honest with yourself and take a good look at how you are feeling that day and analyze the effort you are putting out. You don't want to just go into a training session and not put your best effort forward and look back on it and know you could have done more. Exercise is all about pushing yourself as hard as you can, without significant injury obviously, and pushing past the boundaries you perceive yourself to have physically and mentally. The more you push yourself in training the more motivation, and more importantly, the more discipline you will have spill over into other aspects of your life. You will be stronger mentally and physically, you will have more energy, and you will enhance your life in ways you may not think of right now. Know your limitations, but most importantly learn your strengths.

Written by Dan McCoy, CPT, PLY

Read about why Dan became a personal trainer in [this article](#).

Rice Cooker Stuffing

Serving size 3-4 | 5-minute prep time; Cook time 50-60 minutes | Total time 65 minutes

- 10 oz. Bag Stuffing breadcrumbs
- 1 ½ cups broth of choice
- ½ White onion chopped
- ½ Bell pepper
- 2 Cloves garlic pressed (*½ Tbsp. minced*)
- 1 Celery stalk chopped
- 1 Carrot peeled
- 1 tsp. thyme, oregano, sage, and paprika
- 2 Tbsp. butter (*non-dairy substitute*)
- 1 Egg
- Salt & pepper
- ¼ cup white wine or broth

Directions *Chop the vegetables with a chopper or buy pre chopped. Place the onions, peppers, carrot, celery, butter, and wine in the rice cooker and press start. Let cook for 15 min. While that cooks, in a bowl whisk egg, broth, and seasonings. After the wine has cooked mostly out, add the breadcrumbs to your broth/egg mixture. Toss gently and then add your breadcrumbs to your vegetables in your rice cooker. Bake for an additional 40 min or until the rice cooker shuts off automatically (most rice cooker brands do this).*



COOKING TIPS:

- Make sure you are careful transporting the breadcrumbs mixture to the rice cooker.
- Try placing your rice cooker on a coffee table when cooking for easier access.

SHOPPING TIPS:

- Use trusted sites to do your online shopping.

READ REVIEWS!

- Before making a purchase, filter your items' reviews to get specific feedback. I like to see the "Most Recent" reviews to see if past complaints have been addressed by the manufacturer. I also like to filter for the lowest star ratings. This helps me decide if the complaints being made have similar values or standards that I have.



READ SAFETY FEATURES:

- Many vegetable choppers come with very sharp accessories. Reading and watching videos on how the device works will help you get an idea of how to use the gadget, and whether it is built in a way that feels safe. Reviews can also help you make this decision too!

Written by **Sara Izzo**

Curried Squash Stew

Serving Size: 1.5 cups – 4 servings | 20-minute prep time; Cook time 35 minutes

- 1 Tbsp. vegetable oil
- 1 Yellow onion (*peeled and chopped*)
- 2 Cloves garlic (*peeled and minced*)
- 1 Celery stalk (*including leaves, chopped*)
- ½ teaspoon ground cinnamon
- 1 Large zucchini (*or 2 small*)
- 2 Tbsp. curry powder*
- 3 cups butternut squash
- 1 can (14.5 ounce) low sodium diced tomatoes (*including liquid*)
- 1 can (15.5 ounce) low-sodium white beans or chickpeas (*drained and rinsed*)

Directions Heat a large pot on the stove over medium heat and add oil. Add the onion, garlic and celery and cook for about 10 minutes, until the onion is tender. Add zucchini and curry powder and cook for 10 minutes, stirring occasionally. Add the butternut squash, tomatoes and chickpeas and cover. Continue cooking for about 10 minutes. Serve with cooked brown rice. Optional: For additional flavor, add ½ cup raisins.



Nutrition Information (1.5 cup serving): Calories 234, Total Fat 6 g, Saturated Fat 1 g, Cholesterol 0 mg, Sodium 167 mg, Carbohydrates 41 g, Dietary Fiber 9 g, Total Sugars 10 g, Added Sugars 0 g, Protein 9 g

**Don't have curry powder on hand? While there is no single standard as to what ingredients make up curry powder, you can try the simple recipe below using already ground spices*

Simple Homemade Curry Powder

Yield: 7 tsp. curry powder | 5-minute prep time

- 1 Tbsp. ground coriander seeds
- 1 ½ tsp cumin
- 1 tsp turmeric
- ½ tsp ground black pepper
- ½ tsp chili powder
- ½ tsp ground ginger

Directions In a small bowl, mix all the ground spices. Use immediately, or store in an air-tight container in a cool, dry place for up to 3 months.

Stew Recipe:

[Curried Squash Stew | MyPlate](#)

Curry Powder Blend Recipe:

[Simple Homemade Curry Powder • Curious Cuisiniere](#)



Fun with Food Flavors: Herbs and Spices

Herbs and spices are an easy way to add flavor to your food without adding extra salt or sugar. An herb is the green leafy part of a plant, while a spice comes from seeds, roots, or bark. But it can be overwhelming to learn to cook with herbs and spices! A quick walk down the spice aisle at the grocery store offers an entire wall of choices. So where to start?

The list below provides a few examples of herbs and spices to try, as well as foods they pair well with. This list is not exhaustive – there are many more herbs and spices. You can pair these herbs and spices with any foods you'd like, not just the ones listed. You never know what fantastic flavor combinations you might create!

- **BASIL:** Pairs well with most protein foods, bell pepper, eggplant, tomato, and zucchini.
- **CILANTRO/CORIANDER:** Although these come from the same plant (cilantro is the leaf, and coriander is the seed), these have different flavors and are not used interchangeably in recipes. Cilantro is typically paired with chili, lime, onion, garlic, most proteins, beans, peppers, tomatoes, and avocado. Coriander is often used in curry recipes.
- **CINNAMON:** Warm and sweet, cinnamon can add zest to dessert recipes. But cinnamon isn't just for dessert – it can appear in savory recipes such as curries or stews! Add it to fruit for a hint of sweet flavor. Sprinkle on roasted carrots, winter squash, or sweet potatoes for a cozy side dish.



- **CUMIN:** A warm and slightly citrusy spice that pairs well in many recipes, including meats, chilis, soups and stews, tacos, and vegetable dishes.
- **DILL:** With a slightly more bitter flavor, dill pairs well with seafood, beans, potatoes, cabbage, and cucumber. It is often seen in creamier dishes such as tzatziki, a Greek yogurt sauce-style recipe.
- **FENNEL:** With a licorice-like flavor, fennel goes well with roasted meats and root vegetables.
- **GINGER:** Used in both savory and sweet dishes ranging from stir fries, soups/stews, marinades for meats and tofu, tea, and more.
- **OREGANO:** Often found in Mediterranean-style recipes, oregano pairs well with most animal proteins, beans, tomatoes, bell peppers, mushrooms, zucchini, and potatoes.
- **PARSLEY:** With a fresh and neutral flavor, this herb goes well with classics such as mushrooms, peas, potatoes, beef, chicken, and seafood.
- **ROSEMARY:** The hearty and earthy flavor of rosemary can add depth to most protein dishes, root vegetables, mushrooms, and peas.
- **THYME:** With similar food pairings to oregano and rosemary, these three herbs can go great together for an earthy flavor!
- **TURMERIC:** This spice is a member of the ginger family. It features a bright yellow color and is utilized in soups, curries, marinades, vegetable dishes, and rice dishes. It adds a mild, earthy flavor. It is studied often for anti-inflammatory properties.

(Continued on next page)



- **GARLIC AND ONION** are technically not herbs or spices, but they also can add fantastic flavors to most meat, starch, and vegetable dishes.

How much should you use?

If you are using a recipe, it is easy to follow it as a guide. But what if a recipe calls for fresh herbs, and you only have dried? A good rule of thumb is: 1 tablespoon fresh herbs = 1 teaspoon crumbled/flaked dried herbs = ¼ - ½ teaspoon ground herbs. If you are doubling a recipe, do not double the herbs and spices. Increase by 50%, then add more if needed.

If you are not using a recipe, it is a good strategy good to start small (such as ¼ tsp for a dish with 4 servings, for 2 cups sauce/soup, or for 1 lb. of meat) and work up gradually from there. Use even less (⅛ tsp) for cayenne pepper and garlic powder, which can have stronger flavors.

Unless specified otherwise in a recipe, herbs and spices should generally be added toward the end of cooking to prevent losing the flavors because of prolonged heating. For cold recipes such as a salad, add herbs and spices a few hours before serving -- chill the recipe in the fridge to allow the flavors to blend.

Where to store herbs and spices

Herbs and spices can lose their freshness over time, or even grow mold if exposed to moisture. Dried herbs and spices should be stored in a cool dark place (but not cold – do not store dried herbs and spices in the fridge!). Keep them away from heat, direct sunlight, and moisture. That means do not store them above the stove or on the windowsill! Store them in an airtight container, such as a small jar with a screw-on lid. Whole spices (such as seeds) can last up to 2 years, while ground herbs and spices tend to last only 6 months-1 year. A tip to check if a dried herb or spice is still fresh: rub a small amount of a ground herb/spice between your fingers, then smell to check for a strong aroma. A lack of a flavorful smell means no good

flavor in your food! Do not directly smell pepper – that will irritate your nose.

Fresh herbs can be stored in a plastic bag (not sealed shut) in the crisper drawer of the fridge for a few days. To make them last longer, you can cut the stems of the herbs on the diagonal and place them in a glass of water (filled about 1 inch high) as if it was a vase of flowers. Cover the top of the herbs loosely with a plastic bag and then store in the fridge. Change the water daily. This should make the fresh herbs last closer to 1 week. Heartier herbs like thyme, rosemary, and sage can be stored by wrapping in a damp paper towel and storing in an airtight container/ sealed zip bag in the crisper drawer of the fridge. There is one exception to fresh herbs being stored in the fridge – fresh basil should be stored at room temperature. Basil can turn black and spoil more quickly when refrigerated.

Considerations

While herbs and spices have been researched for a variety of health benefits, it is still possible to get too much of a good thing. It is not recommended to start taking an herbal supplement without first checking with your doctor for safety. Supplements may interact with your medications or cause problems with certain health conditions. Some supplements can cause toxicities due to their dosages. Instead of supplements, stick with flavoring your foods with herbs and spices to reap any positive benefits that these plants have on our health – but in a much more appropriate amount. If you have heartburn or reflux, please be aware that peppers/chili powder, mint, onion, and garlic may worsen symptoms. Cutting back on these items may be helpful to controlling heartburn symptoms. To learn more, check out the references used in this article:

[Herbs | SNAP-Ed \(usda.gov\)](https://www.usda.gov)

[MF3539 Seasoning with Herbs and Spices \(k-state.edu\)](https://www.k-state.edu)

[Cooking with Fresh Herbs - ONIE Project](#)

[Spice_HerbsHandout08.pdf \(azhealthzone.org\)](#)

Written by *Jacquelyn Klunk, MS, RDN, LDN*



Upcoming SBA Events



Feb 26: Teal on the Hill is an annual event that brings members of the Spina Bifida community together from across the U.S. to advocate for issues such as continued funding for the National Spina Bifida Program at the Centers for Disease Control & Prevention (CDC); disability rights; and affordable and accessible healthcare, medical supplies, and technologies.

March 22: World Congress on Spina Bifida Research & Care in Tuscon, AZ. This innovative meeting serves as the preeminent forum for a unique gathering of international Spina Bifida researchers and healthcare professionals specializing in a range of medical disciplines.

Upcoming SBAWP Events

Youth and Teen Retreat December

December 2-4: All Day – Camp Guyasuta

Adult Retreat December

December 9-11: All Day – Camp Guyasuta

6th Annual Shoot for SBAWP

*May 17: 11:00 am - 4:00 pm – Seven Springs
Sporting clays is a form of clay pigeon shooting,
often described as “golf with a shotgun”.*

35th Annual John L. Moroney III Memorial Golf Classic

July 24: 8:00 am - 6:00 pm – Hickory Heights Golf Club

8th Annual Noll-Spratt Golf Scramble

*September 16: 12:00 pm - 8:00 pm
Beaver Valley Golf Club*

For more information regarding events and/or camps and retreats, please visit our website at <https://sbawp.org/events> or call 724-934-9600.

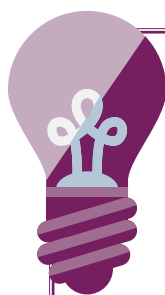


Research Studies

Access to Care Study Do you have a disability and use the healthcare system in the Pittsburgh area (or provide care for someone who does)? We would like to interview you about your experience! We want to understand what makes it difficult to get the care you need and how we might improve access to health care for people with disabilities. Most interviews will be via video call, but accommodations will be made for an alternative interview method if that is not appropriate. Interviews will last approximately one hour, and participants will receive a \$60 prepaid master card with our thanks for assisting us in this research. Please contact the study at kristynfelman@pitt.edu or (412) 692-8189.

Heating Assistance/Low-Income Home Energy Assistance Program (LIHEAP)

The Low Income Home Energy Assistance Program (LIHEAP) helps families living on low incomes pay their heating bills in the form of a cash grant. Households in immediate danger of being without heat can also qualify for crisis grants. The cash grant is a one-time payment sent directly to the utility company/fuel provider to be credited on your bill. These grants range from \$300 to \$1,000 based on household size, income, and fuel type. Remember: This is a grant and does not have to be repaid. You can find out more and apply [here](#).



Do you have ideas for our Newsletter?

If you have particular topics you'd like to see in our newsletter, please reach out and let us know.

Contact us

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Check out our other newsletters and clinic information at: UPMC.com/SpinaBifida