



## Fields of Gold

"Fields of Gold" is a song written and performed by Sting, an English musician. He was inspired to write the song after watching the wind blowing over the shimmering surface of barley fields outside his home. He described them as "waves on an ocean of gold." My favorite version of the song is the one performed by American singer and guitarist Eva Cassidy.

The lyrics say, "I never made promises lightly. And there have been some that I've broken. But I swear in the days still left. We'll walk in fields of gold." The song is about feeling joyous, even if the moment is short-lived. It's also about deciding to make a commitment, even after being unreliable in the past.

This edition of our newsletter is about being inspired to make new commitments to our health and well-being. This includes planning for your family's future, preparing for transition to adult care or for emergencies, advocating for your rights, and exploring new adaptive technologies. We hope that we inspire you to walk (or roll) in fields of gold this autumn.

*Written by Brad Dicianno, MD*

## Planning for the Future

Planning for the future can be difficult but necessary, especially if a parent or caregiver becomes no longer available to provide support. Achieva has good resources to help guide you through this process.

### ACHIEVA Family Trust

Achieva Family Trust has contacts with many reputable legal professionals who specialize in assisting families and individuals with disabilities plan for their future. These attorneys can help you determine what steps will best to meet your needs and draft future planning documents, such as a Last Will and Testament, Special Needs Trust, Power of Attorney, and Living Will.

If you have questions, you can call 412-995-5000, ext. 565 or visit [Achieva's future planning information](#).

Attorneys Familiar with Special Needs Planning & Achieva Family Trust can be found at [Achieva's website](#).

*Written by Amy Kiska, BSW*



## Preparing for Transition

We are fortunate to have both Pediatric and Adult Spina Bifida Clinics. However, the transition to adult care is not always easy to navigate. Transition is not a one-time event but rather a process, a gradual change.

We are all going through transitions all the time. For young adults with complex medical needs, many transitions occur simultaneously. Young people living with Spina Bifida transition to adult roles and responsibilities, to adult bodies, and to all new adult specialists. That is a lot of change! And change is never easy.

We, your Spina Bifida Clinic team, have been working to better support the people we serve in our Adult and Pediatric clinics by continuing to change and improve our transition processes. As stated in the Spina Bifida Association's Guidelines for the Care of People with Spina Bifida: "The primary goal of transition from pediatric to adult health care is to maximize lifelong functioning through the provision of quality, developmentally appropriate health care that continues uninterrupted as the individual moves from adolescence to adulthood".

Our current Transition Protocol is designed to prepare young adults to engage in adult health care and adult responsibilities. We are working to better support our young patients to allow for a smooth handoff of care responsibilities from parents and caregivers to young adults as they are developmentally able.



We want to better assist in the transfer of care to the Adult Spina Bifida Clinic and to other adult providers and health care settings. We hope to provide everyone

with a plan to help them meet their own expectations for optimal independence. It is not always possible to squeeze all these things into an already busy Spina Bifida Clinic appointment.

In response, we recently started a **Transition Clinic**; a clinic dedicated to just these goals. We are so excited to be able to have some of our Adult Spina Bifida Clinic team members who are adults living with Spina Bifida present in our Transition Clinic. Though we are just getting started, young people are already benefiting from meeting and learning from their firsthand experiences.

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

## Building Mental Strength

When trying to accomplish anything worth doing, one thing we can be certain of is that there will be challenges. "**Choose Your Hard**" is one of my favorite quotes for multiple reasons. The first and most obvious is that life is hard. Life may be hard from having Spina Bifida, if you lose someone you love, or if you are having trouble finding a job. How we choose to look at difficulties can have a profound impact on how we react to a situation. If we let a problem derail our forward momentum, this can keep us stuck in a negative cycle of thoughts and actions.



A lot of people with Spina Bifida spend the first 10+ years of their life in and out of hospitals for surgeries and routine doctor visits. These experiences, whether good or bad, will influence how we view hospitals and healthcare, and can build or break trust in doctors, nurses, and healthcare in general.

There are times when I have difficulties seeing positives, but what I have been trying to do over the last 5-10 years, is "reframe" my thinking to "yes, this situation can be difficult, but I can learn from this situation, which will help me to become mentally stronger, and will help others in the future."

"**Pay Now or Pay Later**" is by far the single most important quote I have had stick with me as a kid and into young adulthood. My parents would say this to me frequently, especially when I had to try to tackle difficulties with math, organization, relationships, or any other issue affected by "executive dysfunction." The meaning behind this simple saying is that whether you act on a given situation right now or at a future time, you will eventually need to confront the situation, and it will affect you at some point in your life. We can choose to tackle difficult situations as soon as they arise and work to reframe our mindset. We can ask ourselves, "what can this teach me, and how can I become mentally and/or physically stronger from this?" This approach can give us more confidence and mental strength to become the person we want to be.

*Written By: **Dan McCoy MS, CPT, PLY***



## Yellow Dot Program

The Yellow Dot Program assists citizens in the “golden hour” of emergency care following a traffic crash when they may not be able to communicate their needs themselves. Placing a Yellow Dot decal in your vehicle’s rear window alerts first responders to check your glove compartment for vital information to ensure you receive the medical attention you need. The program is a cooperative effort between PennDOT, the state departments of Health and Aging, the Pennsylvania State Police, the Pennsylvania Turnpike Commission, first responders, and local law enforcement. To find out more or enroll, visit [this link](https://www.YellowDot.pa.gov).

*Written by Monica Albert Still, RN, BSN and Brad Dicianno, MD*

## It’s Time to Vote

Nursing has always involved advocating for patients. For just a moment, instead of advocating for one person, I am going to do it for the community and encourage you to do the same.

The first and easiest step in being an advocate for your community is to vote. According to a study of disability and voting during the 2020 election by Rutgers University, “If people with disabilities voted at the same rate as people without disabilities who have the same demographic characteristics, there would be about 1.75 million more voters.” Imagine nearly 2 million more disabled people telling our government what matters to us! Communities who vote have louder



*Monica sits with Representative Dan Miller on the steps just before Disability Pride PA’s Capitol Crawl to draw attention to the lack of access to the front door of the Commonwealth’s Capitol Building.*



voices and influence over policies that affect their lives. Legislators look up a constituent’s voting record before they meet with that person. If that person has voted in every or nearly every election legislators are more likely to listen and act on the person’s issue.

Pennsylvania has made it easy for you to find out if you are registered to vote, to register to vote, to register to vote by mail, and to find out about accessible voting. All the information you need is available at [Vote.PA.Gov](https://Vote.PA.Gov) or [How to Vote in PA](#).

[Disability Rights PA](#) also provides some guides for accessible voting. If you find barriers to vote related to your disability, call or text Election Protection at **866-OUR-VOTE**. The deadline to register to vote is November 5th, and the 2024 election is on October 21, 2024.

*Written by Monica Albert Still, RN, BSN*

## Senna Tea

Senna is a laxative commonly used to treat neurogenic bowel. The **Senna alexandrina plant** has leaves and pods that contain a substance called **sennosides**, which stimulates the colon to cause a bowel movement. Senna tablets contain 8.6mg of sennosides, and a common dosage is two tablets at night (17.2 mg of sennosides in total).

Sennosides can also be consumed as tea. The general recommendation is to drink 1 cup of senna tea in the evening (1 serving per package instructions). However, note that different brands of tea may contain different doses of sennosides. For example, Smooth Move Tea by Traditional Medicinals contains about 20 mg of sennosides, a slightly higher dose than two tablets. Other brands may contain different doses, and the brewing time can also affect the dosage.

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*Senna is a laxative commonly used to treat neurogenic bowel.*

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You should be aware of some precautions when using senna tea:

1. The FDA's oversight of these types of products is minimal. Any company can sell supplements that may not contain the ingredients or dosage on the label, and which make health claims that may not be true.
2. People who are pregnant should not drink senna tea.
3. Senna teas often contain other ingredients such as licorice root, which should be avoided if you have high blood pressure or low potassium. You should always check the safety of all the ingredients in the tea.
4. Always be aware that ingredients in tea can interact with other drugs you are taking.
5. Taking any supplement at high doses or for long periods of time may be toxic to the liver or other organs.
6. Always let your healthcare providers and pharmacist know about any food supplements you are taking, including those in tea form.

If you are considering senna tea as a treatment for neurogenic bowel, be sure to discuss it with your clinic team first.

*Written by Brad Dicianno, MD  
and Jackie Klunk, MS, RDN, LDN*





## Tips for Slow Cookers

Slow cookers (sometimes called Crock Pots) are convenient ways to cook, but can also pose safety concerns. Here are some tips to use them correctly and safely:

- If your counters are not accessible, place your slow cooker on a table that is low and easy to reach. Make sure this surface is stable.
- Be careful to avoid burns! The pot itself gets very hot so be careful to touch the handles and not the pot itself. If you use a wheelchair, do not put a hot slow cooker (or one full of hot food) on your lap. Take care when opening the lid, as steam that escapes can also burn you.
- Fill the pot to about half full. If it is too full, the food won't cook well. If the liquid is too low, the food may dry out.
- Keep the lid on during cooking. When you lift the lid, you lose heat. It will then take longer for your food to cook to a safe temperature.
- For easy cleanup, you can lightly spray the sides of the pot with cooking spray or use a slow cooker liner bag.
- Let the pot cool before soaking or washing. Big changes in temperature can cause a slow cooker pot to crack.
- Make sure meat/poultry is thawed before adding to the slow cooker (unless the recipe specifically states to use frozen meat).
- Don't store leftovers in a slow cooker. Transfer the food to a container for storage in the fridge or freezer (keep the slow cooker on a stable surface during the transfer process, then carry the empty, cooled pot to the sink for cleaning).
- Don't reheat leftovers in a slow cooker. Use the microwave or stove.

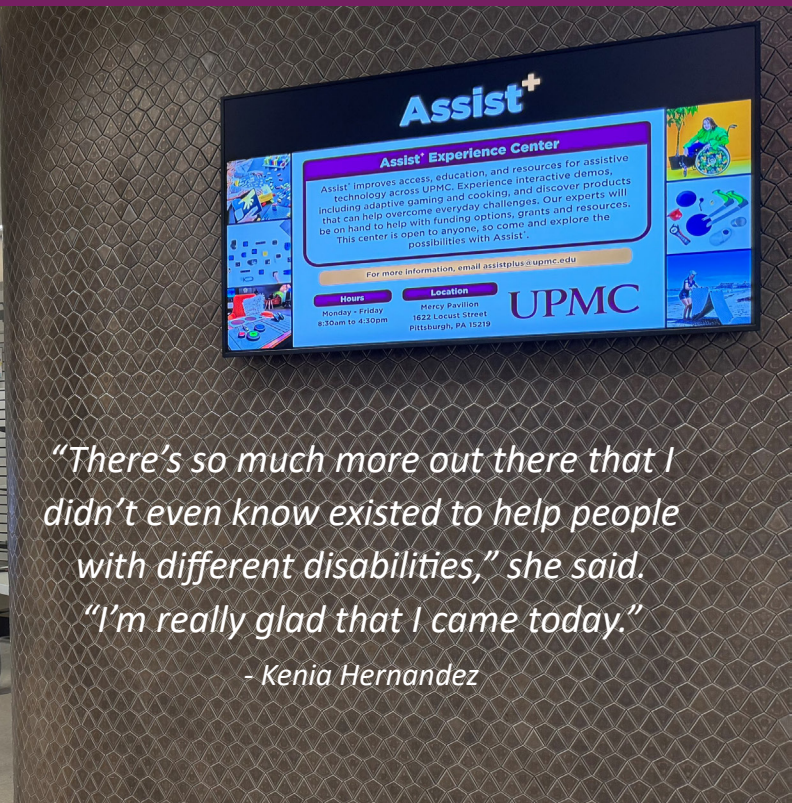
*Written by Jackie Klunk, MS, RDN, LDN*

## Peoples Gas Usage Reduction & Customer Assistance Programs

The Peoples Gas Usage Reduction Program is a weatherization program that helps customers reduce energy costs. It can help you “weatherize” your home and make it more energy efficient, which will help you save money heating and cooling your home. For more info visit [this website](#).

The Peoples Gas Customer Assistance Program offers payment plans for customers with fixed incomes. For more info visit [this website](#).

*Written by Brad Dicianno, MD*



*“There’s so much more out there that I didn’t even know existed to help people with different disabilities,” she said. “I’m really glad that I came today.”*

*- Kenia Hernandez*

## Assist+ Open House

On May 21, 2024 UPMC held a grand opening for our new Assist+ program.

Assist+ improves access, education, and resources for assistive technology across UPMC. The center is led by Mitch Bell, ATP, Innovation Specialist, and Dr. Lynn Worobey.

At Assist+ you can discover and demo a variety of adaptive technologies that can help overcome everyday challenges. This includes technology for interests like video gaming, cooking, or gardening. You can also be introduced to new adaptive clothing designs, disability advocacy materials, and digital tools like smartphone apps or accessibility settings for your phone. Our experts are on hand to help with funding options, grants, and other resources. There are also opportunities to participate in research studies on smart home technologies. You can read more about Assist+ on [Inside UPMC](#).

Assist+ is located on the ground floor of the UPMC Mercy Pavilion near the elevators at the back of the hallway leading to the Rehabilitation Institute. It is open Monday through Friday from 9am - 4pm. You can also call 878-261-6361 or email [assistplus@upmc.edu](mailto:assistplus@upmc.edu) to schedule an appointment.

*Photo Credit: Nathan Langer, UPMC  
Written by Brad Dicianno, MD*



*Top: ASSIST+ exterior. Center: ASSIST+ interior. Lower left: client using adaptive gardening tool. Lower right: Mitch Bell, MS, ATP, Innovation Specialist.*

# Advocacy and Education Activities

Our clinic has been busy with advocacy and education during the Spring and Summer seasons. Dr. Dicianno gave a grand rounds lecture on using assistive technology to prevent skin breakdown to the UPMC Department of Plastic Surgery in February. He also gave a grand rounds lecture on caring for children and adults with Spina Bifida at Cleveland Clinic Childrens Hospital in April. He then gave a keynote speech on caring for adults with Spina

Bifida at Ted Cole Day at the University of Michigan in May. In June, the team attended the Spina Bifida Clinical Care Meeting in Sacramento (photos). Darcie Petrillo spoke on our transition care model. Monica Alber Still presented on incorporating adults with Spina Bifida as team members in Spina Bifida Clinics. Dr. Dicianno moderated a panel on perspectives of adults with Spina Bifida and their caregivers on healthcare.





**SPINA BIFIDA  
ASSOCIATION**

Don't forget that October is an important month.

- October is Spina Bifida Awareness Month
- Oct 25 is World Spina Bifida & Hydrocephalus Day

## **2025 Spina Bifida Clinical Care Meeting** Jun 6 - Jun 7, 2025, Birmingham, AL

Next year's Spina Bifida Clinical Care Meeting has already been announced. We'll be headed to the University of Alabama (UAB) next year to keep up on all the advances in Spina Bifida Care. UAB is home to one of the other large adult Spina Bifida clinics.

*Written by Brad Dicianno, MD*

## **SBAWP Events**

**Sep 21, 2024**

**9th Annual Noll-Spratt Golf Scramble**

Beaver Valley Golf Club

**Sep 27-28, 2024**

**Adult Retreat - Camp Guyasuta**

**Nov 9, 2024**

**11th Annual Girlfriends for Good Purse Bash**

Divine Parish – St. Ferdinand's Oldenski Hall,  
Cranberry Twp

**Dec 6-8, 2024**

**Adult Retreat Dec 6-8 - Camp Guyasuta**

For more information, visit

**<https://sbawp.org/events/>**

## **Low Income Home Energy Assistance Program**

The Low Income Home Energy Assistance Program helps families living on low incomes with energy bills, energy crises, weatherization, and minor energy-related home repairs in the form of a cash grant. Households in immediate danger of being without heat can also qualify for crisis grants. For more info visit **<https://www.acf.hhs.gov/ocs/programs/liheap>**

## **Peer Navigation Program Zoom for Adults with Spina Bifida**

**<https://pitt.zoom.us/j/5709058116?omn=98925951702>**

Meeting ID: 570 905 8116

*Second and Fourth Thursday of every month at 7pm ET*



## **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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Phone: 412-232-8902

Check out our other newsletters and clinic information at: **[UPMC.com/SpinaBifida](https://UPMC.com/SpinaBifida)**



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