

# HOPE & HEALING

A guide to helping survivors navigate through their journey

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Summer 2021 Issue

Northside Hospital Cancer Institute Call Center: [404.531.4444](tel:404.531.4444)



## ASK AN EXPERT



### What is My Role in the Shared Decision-Making Process?

By: *Gena Volas-Redd, MD*

We hear a lot about shared decision-making.

#### What does the shared decision-making process involve?

As medical oncologists, our role is to present the data in a clear and concise manner, so that patients and families can make thoughtful decisions. I always share my opinion based on data as to what I think is best for the patient. Then I allow time for my patients to go home, speak with loved ones and make their own decision based on the information provided. The bottom line is that I do not make someone follow my recommendations if they choose not to do so.

#### Why is shared decision-making so important in the health care setting and specifically oncology?

Our medications are not without side effects. Some are mild, but some are life-threatening. Our drugs have gotten increasingly complicated in terms of side effect management; however, survivorship continues to improve for patients with many cancer types.

#### How do you promote shared decision-making with your patients?

I never try to have the patient make a decision on the very first day I meet with them. I encourage patients to take information on therapies home to read and discuss with family members before making a final decision. These conversations that patients and their families have are thoughtful discussions and should happen over weeks.

#### Are there any specific tools that you use or recommend to patients and/or fellow providers to assist with the process?

I often direct patients to the [National Comprehensive Cancer Network \(NCCN\) guidelines](#). I also share chemotherapy side effects sheets from [chemocare.com](http://chemocare.com) with patients; they are written in terminology that patients can easily understand.

#### What are the advantages and disadvantages of the shared decision-making process?

I have found that if I leave decisions too open-ended with patients, they go to the internet and become even more confused. For example, they may stumble upon a disease-specific blog that has not been approved or written by a health care provider. After reading it, they become confused and have preset decisions based on another person's experience. The bottom line is that patients need time to make decisions regarding their care and treatment.

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## BOOST YOUR HEALTH & WELLNESS



### Hydration and Types of Water: Does the Type of Water Matter?

By: Twyla Jackson, RDN, CSO, LD

Water is important to sustain life. Normally, thirst is a sign of dehydration, but it is not always a reliable indicator. The average person needs 64-72 ounces of fluid per day. Once dehydrated, the body loses water and electrolytes, a group of minerals that are essential for normal bodily functions. When dehydrated, individuals often experience constipation, dizziness, dry mouth, fatigue, headache and nausea. Long-term dehydration can also contribute to problems with the heart and kidneys. Good hydration helps remove waste and

toxins. It also helps to reduce treatment side effects for patients with cancer and survivors.

During treatment, it may be challenging to drink enough fluids due to side effects, such as taste changes, loss of appetite and nausea. Excess fluids may be lost due to fever, vomiting and diarrhea. Many patients and survivors tolerate ice chips better than liquids when nauseated. During times of diarrhea, a good rule of thumb is to drink eight ounces of fluid after each trip to the bathroom.

#### Tips for Staying Hydrated



Start drinking fluids early in the day. The body needs rehydrating after sleep, and this helps to prevent late night trips to the bathroom



Keep a reusable water bottle nearby and sip from it throughout the day



Add a splash of juice, or a slice of fruit or cucumber to enhance the flavor



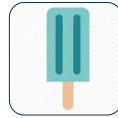
Consider calorie-rich fluids if maintaining or gaining weight is desired



Set a daily water goal and fill a pitcher with that amount



Develop a schedule for times to refill and set reminders



Remember that broths, juices, popsicles, soups, teas and coffee contain some water and can count toward the daily water goal



Try different types of water, especially if the taste of tap water is unappealing

#### Types of Water

**Tap water** is safe for survivors, as long as it is safe for the general population. There are many regulations in place to keep the water supply safe. If there are concerns that treatments performed on the local water supply are not sufficient, boil the water (instructions below) or purchase a home filtration system.

**Bottled or canned water** is convenient, but it is not always better quality than tap water. In fact, some bottled water is from municipal sources. Remember that the containers are not always recycled and oftentimes end up in a landfill or in the ocean. The different types of bottled or canned water may be helpful in different circumstances, but in general, they are not superior to tap water.







**Distilled water** is boiled, and the steam is collected and condensed back into liquid water. **Purified water** is usually tap or groundwater that has been treated to remove harmful substances (bacteria, parasites, fungi). Both of these are good options if there has been a possible contamination to the local tap water supply and the authorities have issued a "boil water" alert. Distilled and purified waters do not contain fluoride, which may help prevent tooth decay.

**Mineral water** comes from a mineral spring and may contain minerals like sulfur, magnesium and calcium. These minerals can also be absorbed by eating a healthy diet. Mineral water is usually more expensive than tap water.

*(continued on page 3)*

## Hydration and Types of Water: Does the Type of Water Matter? (continued from page 2)

### Types of Water (continued)

-  **Spring or glacier water** providers claim to bottle the water at the source. These waters may contain some of the minerals that are in mineral water. They are not always filtered or tested, which could be a potential risk.
-  **Sparkling water** is infused with carbon dioxide gas under pressure. Different forms of sparkling water include club soda (which often has added minerals), soda water and seltzer water. The carbonation makes it similar to soft drinks, but it may have less calories. Some sparkling waters have added sugars or artificial sweeteners, so check the label if relevant. Some people report that carbonation helps to manage thick saliva or secretions. Others experience more gas and bloating due to carbonation and may prefer plain water.
-  **Vitamin water** contains vitamins as well as other ingredients for taste. These may include added sugars or artificial sweeteners and flavors that mimic the taste of some fruit. Some types of vitamin water also contain caffeine. The added vitamins may not be appropriate during certain types of cancer treatment.
-  **Flavored water** is water that contains natural or artificial flavors. It sometimes contains added sugars or artificial sweeteners. Flavoring water may help with taste, and thus be an aid to drinking adequate fluids. Those with added sugars also provide a source of calories, but may also promote tooth decay. It is best to rinse with plain water after drinking flavored water to help cleanse the enamel.
-  **Alkaline water** has a higher pH than tap water and contains alkaline minerals. Some people believe that an alkaline diet may prevent, reduce or cure various diseases, including cancer. Current scientific studies do not support the theory that alkaline water or alkaline diets have this effect in humans. Alkaline water may decrease acid in the stomach, lowering its ability to kill harmful bacteria.
-  **Oral rehydration solutions** are a type of fluid replacement used to prevent and treat dehydration, especially due to diarrhea. They involve drinking water with modest amounts of sugar and salts, usually sodium and potassium. Commercially available brands include DripDrop<sup>®</sup>, Pedialyte<sup>®</sup>, Hydralyte<sup>®</sup>, Ensure<sup>®</sup> Rapid Hydration, Liquid I.V.<sup>®</sup> and various sports drinks, among others. Below is a recipe for a do-it-yourself version of an oral rehydration solution.

Tap water is generally safe for all cancer survivors and is likely the least expensive option. The other options are not superior (or more hydrating), but individuals may choose them based on preference, convenience or their doctor's recommendations.

**Boil Water Advisory:** *Authorities issue a boil water alert when pressure is lost in the water line and there is the possibility of any foreign substance entering the system. During the advisory, it is best to boil tap water vigorously at or near 212° F (100° C) for at least one full minute to kill any disease-causing bacteria that may be present in the water. During a boil water advisory, use boiled tap water for food preparation, cooking, drinking, making ice and brushing teeth.*

### Oral Rehydration Solution and Flavored Water Recipes

#### World Health Organization Oral Rehydration Home Solution\*

##### Ingredients:

- ½ teaspoon table salt
- ¼ teaspoon Morton<sup>®</sup> Salt Substitute
- ½ teaspoon baking soda
- 2 tablespoons table sugar
- Add tap water to make one liter

Use household measuring spoons, not silverware, to measure the ingredients.

##### Directions:

1. Add about half of the needed water to the one-liter container.
2. Add the dry ingredients, stir or shake well; add the remaining water to make a final volume of one liter.
3. Add Nutrasweet<sup>®</sup> or Splenda<sup>®</sup> based flavoring of choice, if desired.
4. Chill until cold and sip as directed. Discard after 24 hours.

##### Nutrition Information:

Each liter provides Sucrose: 24 grams, Sodium: 76 milliequivalent, Potassium: 18 milliequivalent, Chloride: 68 milliequivalent, Bicarbonate: 26 milliequivalent with osmolarity of 268 milliosmole.

\*Recipe from: *A Patient's Guide to Managing a Short Bowel*, 2nd edition; Carol Rees Parrish, MS, RD; 2013. Updated: 1/2016.

#### Spend with Pennies Flavored Water\*

##### Ingredients:

- 2 cups fresh mixed berries or 1 each lime, orange, ½ lemon (all sliced)
- 2 sprigs mint, ginger or other herbs, optional
- 3 cups ice
- Water to fill pitcher

##### Directions:

1. Place fruit and herbs in a two-quart pitcher along with about one cup of water (no need to measure).
2. Using the end of a wooden spoon, slightly crush the fruit and optional herbs to release the flavors.
3. Add three cups of ice and fill the pitcher with water.
4. Steep about one to two hours and enjoy!

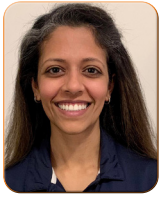
##### Nutrition Information:

Calories: 34, Carbohydrates: 9 grams, Protein: 1 gram, Fat: 1 gram, Saturated Fat: 1 gram, Sodium: 7 milligrams, Potassium: 53 milligrams, Fiber: 1 gram, Sugar: 7 grams, Vitamin A: 205 international unit, Vitamin C: 1 milligram, Calcium: 6 milligrams, Iron: 1 milligram.

Nutrition information provided is an estimate and will vary based on ingredients used.

\*Recipe from: [spendwithpennies.com/naturally-flavored-water-amazing-healthy-thirst-quenchers/](https://spendwithpennies.com/naturally-flavored-water-amazing-healthy-thirst-quenchers/)





## Pelvic Floor Dysfunction in Survivors

By: Mira Merille, PT, DPT, WCS

Cancer treatments are designed to save lives, but these treatments can also unintentionally affect the structure and function of the pelvic floor tissues in men and women. This may result in pelvic floor dysfunction and adversely impact quality of life in survivors. The pelvic floor is a group of muscles, ligaments and fascia in the shape of a bowl at the base of the pelvis. These structures extend from the pubic bone to the tailbone and also between the sit bones. They serve an integral role in bowel, bladder and sexual functioning as well as provide pelvic organ support.

Pelvic floor dysfunction occurs when there is too much or too little tension in the pelvic floor muscles causing problems with coordination, endurance and strength. Common complaints of individuals with pelvic floor dysfunction include urinary or fecal leakage; urinary urgency and frequency; pain with gynecological exams or intercourse; difficulty emptying bowels or bladder; feeling of fullness in vagina and/or rectum and general pain in the abdomen, hips, low back or pelvis.

Treatments for several cancers, including anal, colorectal and bladder cancers can contribute to pelvic floor dysfunction. Surgery may remove or weaken key structures used in bowel and bladder control along with bowel and bladder emptying. Radiation can cause fibrosis, atrophy, shortening and impaired function of the radiated tissue. This can lead to accidental bowel leakage, constipation, urinary leakage, urgency, frequency, difficulty with bladder emptying and sexual dysfunction. Urinary leakage may occur in men who have had surgery and/or radiation for prostate cancer. This occurs because removing or radiating the prostate gland can sometimes affect the muscles and nerves that help maintain bladder control. Moreover, women with gynecological cancers who undergo surgery and/or radiation treatments may have a narrowing of the vaginal canal related to fibrosis. This can lead to pain with intercourse, pain with gynecologic exams or generalized pelvic pain. Additionally, these treatments can weaken the pelvic floor and cause hormonal changes resulting in urinary leakage, urgency and frequency.

Pelvic health physical therapists are specialized in treating pelvic floor dysfunction and can provide an initial evaluation to determine the root cause of each patient's symptoms. The findings are put into context along with medical history, cancer treatments and specific risk factors. An individualized treatment plan is developed, and recommended therapies may include vaginal dilators and massage to address tightness in the vaginal canal or pelvic muscles, scar tissue mobilization, biofeedback for pelvic floor retraining, education on healthy bowel and bladder habits and/or pelvic floor and core muscle strength training.

If you feel you may have pelvic floor dysfunction, consider the statements below. If any ring true, it may be best to discuss concerns with your medical provider and receive further evaluation.

- I sometimes leak urine with coughing, sneezing or with sensation of urgency.
- I feel like I have to urinate frequently or do not empty my bladder completely.
- I wake up more than once per night to urinate.
- I feel pressure or heaviness in the vaginal region.
- I have difficulty with bowel control or have urgency with bowel movements.
- I feel like I have to strain during a bowel movement or do not empty my bowels completely.
- I have pain or cannot tolerate intercourse and/or gynecologic exams.
- I have pelvic pain when active, during exercise or with sitting.
- I have pain at the site of my surgical scars.

Click [here](#) to learn more about Oncology Rehabilitation services (including virtual visits) offered at Northside Hospital. A physician referral is required for therapy services. If you have a question or want to schedule an in-person or virtual appointment, please contact the scheduling team at [404.236.8030](tel:404.236.8030).

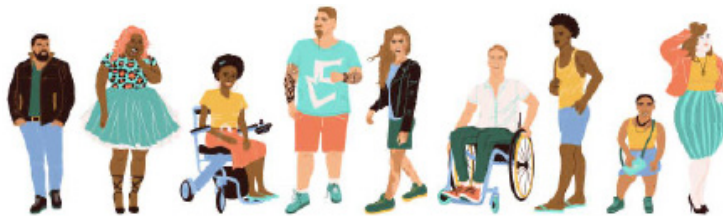


## Building a Positive Body Image During and After Treatment

By: Christina Austin-Valere, PHD, LCSW

Cancer treatment can have a significant physical and emotional impact on patients and survivors. Several changes can occur during this journey, and some are more obvious than others. Physical changes can range from the more noticeable side effects of hair loss, weight changes, disfigurement and surgical scarring to the less obvious side effects including fatigue, pain, insomnia as well as changes in libido and fertility. Body image is directly related to the way we think, feel and perceive our sense of beauty or attractiveness. Adapting to these physical changes can be different for everyone. It is, therefore, vital to take the time to grieve the losses experienced and acknowledge the psychological adjustment needed.

Building a positive body image is twofold in that it helps individuals take a more positive approach to their physical appearance and worry less about how others perceive or even react to them. It creates the space for individuals to think more about the resiliency of their bodies rather than the flaws. Creating a positive body image can be achieved by reminding oneself that the inner person is still the same despite the external changes. Other recommended self-help



efforts include joining a support group to share experiences with other survivors, utilizing clothing that accentuates one's positives and surrounding oneself with positive and non-judgmental people. Patients and survivors can also take charge of their bodies with healthy habits such as exercise, nutrition, adequate hydration and sleep.

Knowing where to seek help to address body image concerns is key. Talk to your health care team about any concerns and request a referral to a therapist who can help address any feelings of anxiety, depression, fear and uncertainty, if needed. Also request rehabilitation to manage any physical limitations.

**Remember that you are the center of and the best advocate of your care!** For more information on [Northside Behavioral Health](#) services please call [404.851.8960](tel:404.851.8960) or [email](#).



## STORIES OF HOPE & HEALING\*

### Survivor Story: Meet Roddie

**What are the events that led up to your cancer diagnosis?**

I was always very in tune with my body and did all the right things like eating well and exercising regularly, but I began to feel like something was not quite right. One day, I noticed some spotting and immediately felt that something was wrong. I called my trusted physician of over 20 years, and he did a biopsy. He called me a few days later with the news that I had uterine cancer and quickly put me in touch with a gynecologic oncologist at Northside Hospital Cancer Institute.

**What treatment did you receive?**

Within another two days, I was in the oncologist's office where he officially confirmed my diagnosis and began telling me about treatment options. I underwent surgery for uterine cancer and had a total hysterectomy, immediately followed by chemotherapy

(for about one year) and radiation therapy (2 weeks).

**How and where did you receive support during your treatment and recovery? Did you utilize patient support resources at NHCI?**



In the beginning of my diagnosis and treatment, I isolated myself. I did not like myself at the time and had given up on life, but then one day while checking in for an appointment at the oncologist's office, I noticed a piece of paper on the wall. It was an invitation to join an organization that supports individuals on their cancer journeys called Network of Hope. Once I began to feel a little better, I started going to the meetings and felt like my life started over. I had a brand-new group of friends who could relate to what I was going through and who were there to care

*(continued on page 6)*

**Survivor Story: Meet Roddie** *(continued from page 5)*

for and support me. I also attended Camp Hope, which is a retreat for survivors hosted by Northside.

**What advice do you have for someone navigating their treatment and recovery journey?**

Allow the doctors and nurses to attend to your needs. Also, get involved with a support group as soon as you can. It is important to have people around who understand what you are going through. You will also need a spiritual group. Stay close to family and do not isolate yourself.

I would also recommend volunteering when ready. I volunteer because I want to give back as much as was given to me. It feels so good to volunteer. I recognize that life is a gift and a privilege. Since my diagnosis, I have learned that you only have one chance at life, and I realized that I had not been living it the way it was supposed to be lived. Now I am so happy! I have my new friends and my new life. I am even breathing differently. I actually

experienced cancer, surgery, radiation and chemo for over a year and have not missed a beat. I do not really think about it; all I think about is living.

**How far out are you from treatment or is treatment ongoing?**

I am five years out and I recently went to the doctor and was declared clinically cured. So I am celebrating and embracing being healthy. I am doing more now than before my diagnosis. My plan is to do something different every week! I spend lots of time with my grandkids and enjoy shopping, as well as going on hikes and walks.

**Closing Thoughts**

I know who I am, I know what I want and I will not settle for less. I am explosively exploring everything; I look at life differently, and through this journey I found myself. I sparkle from within, and I do not allow people to dictate my journey. I now see that the world is a beautiful place.

\*Patients' stories are based on individual experiences. The process from diagnosis through treatment may vary as well as symptoms and side effects.

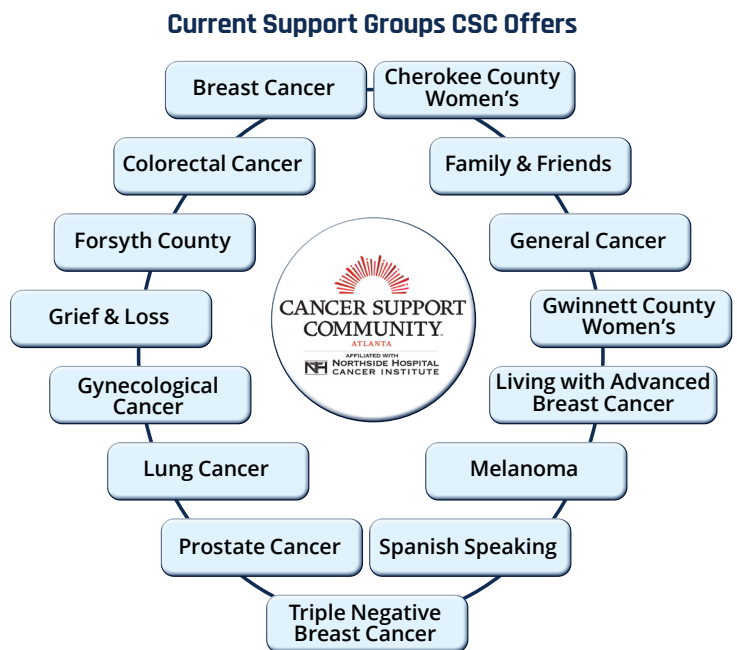


**COMMUNITY SUPPORT & RESOURCES**

**Virtual Support Groups to Continue at Cancer Support Community Atlanta**

Support groups can be a lifeline for people experiencing challenging situations. For a survivor, attending a group with others, who understand their unique experiences, can be an important part of their recovery. These groups often cover a variety of topics including sharing information about ongoing treatments, side effects, follow-up scans and adjusting to life after cancer. Cancer Support Community (CSC) Atlanta offers a variety of groups for patients, survivors and caregivers, all led by licensed mental health professionals.

When the pandemic began, CSC Atlanta transitioned all support groups to a digital platform in order to provide a safe way for participants to receive the much-needed support. The response to this change from attendees was so overwhelmingly positive that CSC Atlanta decided to continue its virtual option indefinitely. Now, people throughout the state of Georgia can participate in support groups, regardless of where they live. Additionally, when CSC Atlanta reopens, people will also be able to attend in-person at the new location: 1100 Johnson Ferry Road NE, Suite LL90 near the Northside Hospital Atlanta campus.



Please check CSC Atlanta's [website](#) to learn more about the different groups and when they are offered. If interested in joining a group, please email Program Director [Emily Brown](#) for more information.



## GET INVOLVED



### Spotlight on Network of Hope: Interview with Ana Maria

**How long have you been involved with Network of Hope and specifically with the Spanish request aspect of the program?**

I have been a volunteer with Network of Hope (NoH) since November of 2013. I began with my six-week training, and I never stopped. Ever since the beginning, I have volunteered with requests from Spanish-speaking patients.

**In what ways do you assist Spanish-speaking patients?**

I serve as a mentor to Spanish-speaking patients and participate in health fairs and community screenings in Spanish-speaking areas. Northside Hospital offers trained and certified professional interpreters to all patients. My role is in a volunteer capacity. I offer conversation and supportive talks as a mentor and support the Northside community outreach team at events and activities.

**Please share a recent patient anecdote.**

Since early April, I have been mentoring a Spanish-speaking woman with breast cancer. We have been speaking after her chemotherapy sessions, and she usually calls me when she has a new symptom. I share my experience with her and advise her to call her doctor when her questions go beyond my training. From the beginning, I suggested that she watch TV (as a distraction) when she is not feeling well. I told her that I always had the TV on during the day, which helped distract me from the pain I was experiencing. She told me that she does not normally watch TV; however, on a recent call, she mentioned that she watched a little TV to help distract her from her bone pain.

**What type of training is involved?**

In general, to become a NoH volunteer, one has to become part of the Northside Hospital Auxiliary. The Auxiliary trains all volunteers on hospital processes. I am currently a member of the Auxiliary Board and serve as the Auxiliary Special Projects Chair. Volunteers interested in patient visits must shadow an experienced NoH volunteer for six in-person patient visits. At the end of in-person training, the trainee leads the patient visits to demonstrate her/his ability to speak with patients. NoH volunteers are also offered continual training from hospital staff.

**Is there anything else about NoH or your experience that you would like to mention?**

Yes! Camp Hope is an annual three-day weekend retreat held in April for cancer patients. I have attended Camp Hope as a patient and a mentor. As a patient, the experience was overwhelmingly heartwarming, poignant and fun, inspiring lots of hope for the future. As a volunteer, it was amazing to be able to discuss concerns and participate in activities that bring smiles to the faces of the attendees. The camaraderie experienced by everyone at the retreat is wonderful. I also have to mention that I had the opportunity to be a model at the closing ceremonies of Tennis Against Breast Cancer (Northside Foundation Event), which was great fun!

**Who can someone contact to volunteer/get involved with the program?**

For more information, email [Network of Hope](mailto:NetworkofHope@northside.com) or call [404.303.3676](tel:404.303.3676).

#### UPCOMING CANCER AWARENESS MONTHS

**July:** Sarcoma and Bone Cancer

**September:** Leukemia and Lymphoma, Prostate Cancer, Gynecologic Cancer and Thyroid Cancer

Do you have a question you would like answered by an expert or a story to share in a future issue of Hope & Healing? If so, please send your questions or stories to [survivornewsletter@northside.com](mailto:survivornewsletter@northside.com).



## EVENTS & CANCER CELEBRATIONS

### CANCER SCREENING & PREVENTION

#### Skin Cancer Screening

July 15, 2021, from 6-8 p.m. @ Northside/Alpharetta Medical Campus

#### Prostate Cancer Screenings

August 19, 2021 from 5:30-8 p.m. @ Northside/Alpharetta Medical Campus

September 16, 2021 from 5:30-8 p.m. @ Northside Hospital Cancer Institute Radiation Oncology- Atlanta

#### Built to Quit – Smoking and Tobacco Cessation Course

Next 6-week session start date: September 14, 2021

Classes are currently web-based and meet weekly.

They are conducted primarily in a group setting which encourages participants to learn from each other.



### COMMUNITY EVENTS

#### Relay for Life

##### Relay for Life of Atlanta Family Reunion Caravan & Party

July 25, 2021 @ 2:45 p.m. @ E. Rivers Elementary School & Georgia Power Corporate Headquarters in Atlanta

##### RFL of Cherokee County

September 17, 2021 @ 6 p.m. @ Etowah River Park in Canton

##### RFL of Bibb County

September 18, 2021 from 11 a.m.-3 p.m. @ Luther Williams Field in Macon

##### RFL of Baldwin County

September 25, 2021 from 11 a.m.-3 p.m. @ Baldwin County Soccer Complex in Milledgeville

##### RFL of Forsyth County

October 22, 2021 from 6-11 p.m. @ Cumming Fairgrounds in Cumming

#### NHCI Sponsored Cancer Walks/Events

##### SagerStrong Foundation 3K Stadium Fun Run

August 22, 2021 @ 8 a.m. @ Truist Park

##### Team Maggie 5K/10K

September 18, 2021 from 7:30-10:00 a.m. @ King's Court Chapel in Roswell

##### Ovarian Cancer Research Alliance Ovarian Cycle

September 26, 2021 from 1-5 p.m. @ TURN Studio in Sandy Springs

##### Georgia 2-Day Walk for Breast Cancer

October 2-3, 2021 @ 7 a.m. @ the Atlanta Marriott Marquis

##### Leukemia & Lymphoma Society Light the Night

October 2, 2021 @ 7 p.m. @ Piedmont Park

##### Komen Greater Atlanta More Than Pink Walk – Virtual

October 9, 2021 @ 10 a.m.



### NORTHSIDE EVENTS

#### Tennis Against Breast Cancer benefiting Northside Hospital's Breast Care Program

October 1, 2021 in Cherokee

October 8, 2021 in Forsyth

October 15, 2021 in North Fulton

October 22, 2021 in Gwinnett

#### Paint Gwinnett Pink 5K Walk/Run for Breast Cancer

October 23, 2021 @ 7 a.m. @ Coolray Field in Lawrenceville

#### Wine Women & Shoes benefiting the Northside Hospital Cancer Institute

November 14, 2021 @ 1 p.m. @ The Hotel Avalon

