

# TOGETHER

A newsletter for patients and families from the Comprehensive Cancer Support Program and the Patient and Family Advisory Council at the N.C. Cancer Hospital

VOLUME 1, ISSUE 2

SPRING 2022

## INSIDE THIS ISSUE:

Nurse Navigators	1
Thank you, Staff	1
Cancer Survivorship Summit	2
Covid-19 Update	2
Getting Around the Hospital	2
Meet Our PFAC	3
Comprehensive Cancer Support Program	4

## NURSE NAVIGATORS

### What is a nurse navigator?

A nurse navigator is someone who connects patients to their healthcare team and helps throughout a patient's treatment. By assisting patients and their families, they ease some of the weight that comes with a diagnosis. Navigators share information about managing symptoms and help patients with their specific, individual care plan. Many times, before someone becomes a nurse navigator, they work on the floors of the cancer hospital. This lets them gain a lot of experience and become a knowledgeable resource. A nurse navigator works as a team with other healthcare professionals to make sure patients get the best care possible. They can help to coordinate the many moving

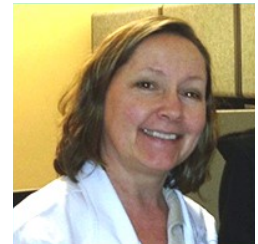
parts of a patient's care, including your care plan between different doctors and care specialists.

### What can a nurse navigator do for you?

Nurse navigators are here for you! Every cancer patient is assigned a nurse navigator who is associated with their doctor. Navigators are happy to help in any way that they can. Some great questions to ask your coordinator could be, "What can I expect along the way?" or "What has helped other patients who have received these treatments?" Your navigator can also help organize your different appointments. Because of COVID-19, navigators are not in the clinic at all times, but they are happy to chat. You can reach your navigator over the phone,

through email, or through MyChart. Do not hesitate to reach out. If your navigator does not have an answer to your questions, they will find someone who does!

If you don't know who your navigator is, speak with your provider and ask to be connected to your nurse navigator.



**Special thanks to Amy DePue, MSN, RN, OCN, CBCN, for her contribution to this piece.**

## THANK YOU TO OUR HOSPITAL STAFF!

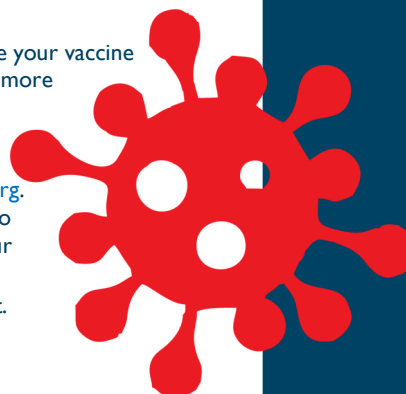
The Patient and Family Advisory Council (PFAC) and the Comprehensive Cancer Support Program (CCSP) want to express our heartfelt thanks to all of the staff at the cancer hospital. The hospital staff has worked tirelessly under difficult conditions throughout Covid. We are so grateful for your kindness and great care.

# UPDATE ON COVID-19

All adults and children 5 years and older are eligible for the COVID-19 vaccine. Most cancer patients can be vaccinated. The Centers for Disease Control and Prevention (CDC) recommends that people with weakened immune systems receive an additional dose of the primary vaccine series. Boosters are also available for those 12 and older.

In addition to the COVID-19 vaccine, you should continue to wear a mask, wash your hands regularly, and practice social distancing. Just like other vaccines, the COVID-19 vaccine can cause minor side effects. If you have any questions about the vaccine series or any potential side effects, contact your doctor.

To schedule your vaccine or to learn more about boosters, visit [YourShot.org](https://YourShot.org). You can also contact your local health department.



# CANCER SURVIVORSHIP SUMMIT

**2022 NC Cancer Survivorship Summit (a virtual event) will take place on Friday, May 6th - Saturday May 7th, 2022**

This summit is for patients, survivors, thrivers and caregivers only. Join other cancer survivors and thrivers to celebrate your journeys and experiences. Gain knowledge, skills and tips from

cancer experts, Take part in healthy living activities and be empowered through engaging sessions that will equip you throughout your survivorship journey.

You can connect to resources, services and support for patients and caregivers.

**Remember you are not alone!**

To register and learn more, go to the website:

<https://ncpha.memberclicks.net/cancer-survivorship-summit>

Or contact:

Sarah Arthur, Comprehensive Cancer Control Program Coordinator

[sarah.arthur@dhs.nc.gov](mailto:sarah.arthur@dhs.nc.gov)

North Carolina Cancer Prevention and Control Branch

**2022 NC CANCER SURVIVORSHIP SUMMIT**

Friday, May 6th - Saturday, May 7th 2022



# GETTING AROUND THE HOSPITAL

## WAYFINDING WITH THE UNC HEALTH APP

Did you know there's an app that helps patients and visitors find their way through the hospital?

The app is free and available for both Apple and Android devices. You can think of it as Google Maps for the hospital.

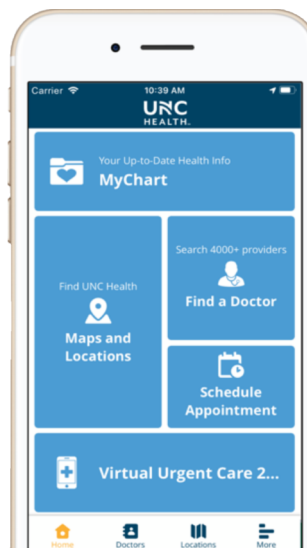
With this handy app, you can get everything from turn-by-turn directions to UNC hospitals, directions inside the hospital, UNC Urgent Care wait times, access to your medical records, and much more.

## Other helpful things you can do on the app are:

- find a doctor
- make an appointment
- have a virtual visit and be able to add family members
- mark where your car is parked and follow directions to it

## How to get the app:

You can download the app by searching for "UNC Health" on the Apple App store, or the Google Play store. Or text "UNCAPP" to 43506.



During the pandemic the PFAC organized roughly 9,000 meals for hospital staff.



Loretta Muss with a “few” of the thousands of baked goods she baked for the staff.

# MEET OUR PFAC MEMBERS



**Loretta Muss, RN, BA**

**Coordinator, Patient and Family Advisory Council, N.C. Cancer Hospital Coordinator, Patient and Family Centered Care, UNC Health**

**What led you to the Patient and Family Advisory Council (PFAC) and why is it a good fit for you?**

Loretta Muss and her husband moved from Vermont to Chapel Hill to join UNC in 2009. In Vermont, Loretta created an organization that provided support to cancer patients throughout the state. At UNC, she was tasked with setting up an advisory council for the Cancer Hospital. “I was flying by the seat of my pants,” she says, but within a year the council was off the ground. Loretta describes herself as a social animal who believes that one of the greatest qualities someone can have is kindness. “This has been a joyous job. I love what I do, and I work with incredible people,” she says. “Every day something positive happens. Whether that is making a connection with a patient, a staff member saying, ‘thank you’, creating a new program, or presenting a project on the national stage.”

**Tell us about a special project or experience you have had with the PFAC.**

In March 2020 when the coronavirus pandemic began, Loretta and PFAC president Larry Hutchison decided that they had to do something to support the staff. “We raised funds amongst ourselves, neighbors, anyone we knew. We started by providing 50 dinners in the cancer hospital.” In her home kitchen, Loretta baked desserts to accompany the meals. “I baked

a lot,” she laughs. “In the end we were probably making 375 desserts a month.” The PFAC organized a total of roughly 9,000 meals for hospital staff. Support poured in from everywhere—restaurants gave large discounts and packaged hundreds of individual meals; Loretta’s neighbors dropped off baking supplies and envelopes with cash; and when money dwindled UNC Health and the Lineberger Comprehensive Cancer Center stepped in and committed funds so the meals could continue. “It was unbelievable to see the generosity of this community! Even more than that it brought you to your knees to see how grateful the staff was.”

**What would you like to share with our newsletter readers?**

“The work the PFAC does is changing minds in looking at a person not as a patient in a gown but as a dad, a teacher, a president of a company. It all boils down to making a cancer patient’s journey better because we are using the experience of those who have come before.”



**Larry Hutchison**

**President, Patient and Family Advisory Council**

**What led you to the Patient and Family Advisory Council (PFAC) and why is it a good fit for you?**

Growing up, Larry Hutchison’s parents were a huge influence on his life. His father always believed in giving back to the community and the day that Larry retired his father reminded him, “You’ve done great, son, but don’t forget to give back!” Not long after, Larry’s calling found him. His best friend was diagnosed with cancer

and Larry stepped in and became the primary caregiver. Larry, who PFAC members affectionately call “Hutch,” spent many days by his friend’s side during appointments and in the bone marrow transplant unit. In fact, Larry was in the hospital so often that one day in 2011 he was approached and asked to join the PFAC. “UNC does a wonderful job and is an incredible hospital, but I felt there were some things we did not take into context about a caregiver. A caregiver is an essential part of the healing process.”

**Tell us about a special project or experience you have had with the PFAC.**

Since joining the PFAC in 2011, Larry has been involved in countless projects, but several stand out. Along with another PFAC member, Ryan Keith, he started Caregiver Conversations.

Last year, Larry and Loretta Muss launched the effort to provide meals to hospital staff during the coronavirus pandemic. However, one of his proudest accomplishments is getting all PFAC members more involved. Larry’s passion is contagious, and he has a knack for finding the right person for the job. “Since I became president, my priority was to get every council member engaged. We have a lot of talent on our committee. Our members are educated, passionate, and from all walks of life so why not use that to the best of our ability?”

**What would you like to share with our newsletter readers?**

“Giving back is hugely important in life. It’s not always about writing a check. It’s about remembering that nobody wants to be in the hospital. People don’t want to get sick, but they do. It’s part of the life cycle. But if others are giving back their time and energy to make the situation for those in the hospital a little better, that is very powerful.”

# COMPREHENSIVE CANCER SUPPORT PROGRAM (CCSP)



The Comprehensive Cancer Support Program (CCSP) provides a wide range of educational and clinical services for cancer patients and their families. We are here to help you and your family.

**Where:** N.C. Cancer Hospital, Ground Floor Tony Williams Lobby  
**Phone:** (984) 974-8100  
**Website:** [www.unclineberger.org/ccsp](http://www.unclineberger.org/ccsp)  
**Email:** [ccsp@med.unc.edu](mailto:ccsp@med.unc.edu) to join the monthly listserv

## THE MARY ANNE LONG PATIENT AND FAMILY RESOURCE CENTER (PFRC)

PFRC is the home base for your support, education, referrals and resource connections including an education relaxation room, and boutique for head coverings.  
<https://unclineberger.org/pfrc>

## ADOLESCENT & YOUNG ADULT PROGRAM (AYA)

AYA Program offers support, resources, events and connections with other young people coping with cancer.  
[uncaya.org](http://uncaya.org) or email [ayacancer@med.unc.edu](mailto:ayacancer@med.unc.edu)

## COUNSELING & PSYCHIATRY

Services are offered by our psychiatrists, psychologists, and counselors and include compassionate support and symptom management for the challenges that often come with cancer diagnosis. Open to patients and caregivers.  
To schedule an appointment: 919.966.3494

## FINANCIAL & LEGAL ASSISTANCE

UNC Pro Bono Legal Clinic helps prepare future health planning documents. Patient Assistance Coordinator along with your nurse navigator & social worker can help you find resources that may lessen the financial burden of a diagnosis. 984.974.8112

## CAREGIVERS

Caregiver Conversations is a supportive program just for caregivers caring for a patient with a cancer diagnosis. To register go to  
<http://www.unclcn.org/caregiverconversations>

Caregivers play a huge role in the patient's recovery. We are there to help you every step of the way. Visit our caregiver website: <https://caregivers.web.unc.edu/>

## SURVIVORSHIP

Survivorship care focuses on your needs from the time of diagnosis through the balance of your life. We offer an education program that focuses on emotional care, nutrition, physical exercise, and medical management after cancer treatments. Survivorship care plans are offered by your medical team.

## HEALTH COACHING/PHYSICAL ACTIVITY

These services are available to help you include physical activity and relaxation into your lives: yoga, massage therapy, Get Real and Heel (a 16-week free exercise program), Healthscore (a remote health coaching program), and individual consultations. [carly\\_bailey@med.unc.edu](mailto:carly_bailey@med.unc.edu)

## DIETITIANS

Dietitians from the Outpatient Oncology Team provide nutrition counseling and work with patients undergoing surgery, chemotherapy, and radiation.

## INTEGRATIVE ONCOLOGY CONSULTS

Consults offer personal health strategies by combining complementary therapies that are safe and effective with conventional medical approaches. 919.966.3494

PATIENT AND FAMILY RESOURCE CENTER (Resource Navigation/Support Triage/Dietitians)	984.974.8100
COUNSELING & PSYCHIATRY	919.966.3494
FINANCIAL & LEGAL ASSISTANCE	984.974.8112
HEALTH COACHING/PHYSICAL ACTIVITY/YOGA/MASSAGE	919.445.4255
INTEGRATIVE ONCOLOGY CONSULTS	919.966.3494

◆ Thanks to the generosity of our community of supporters most CCSP services are provided free of charge.