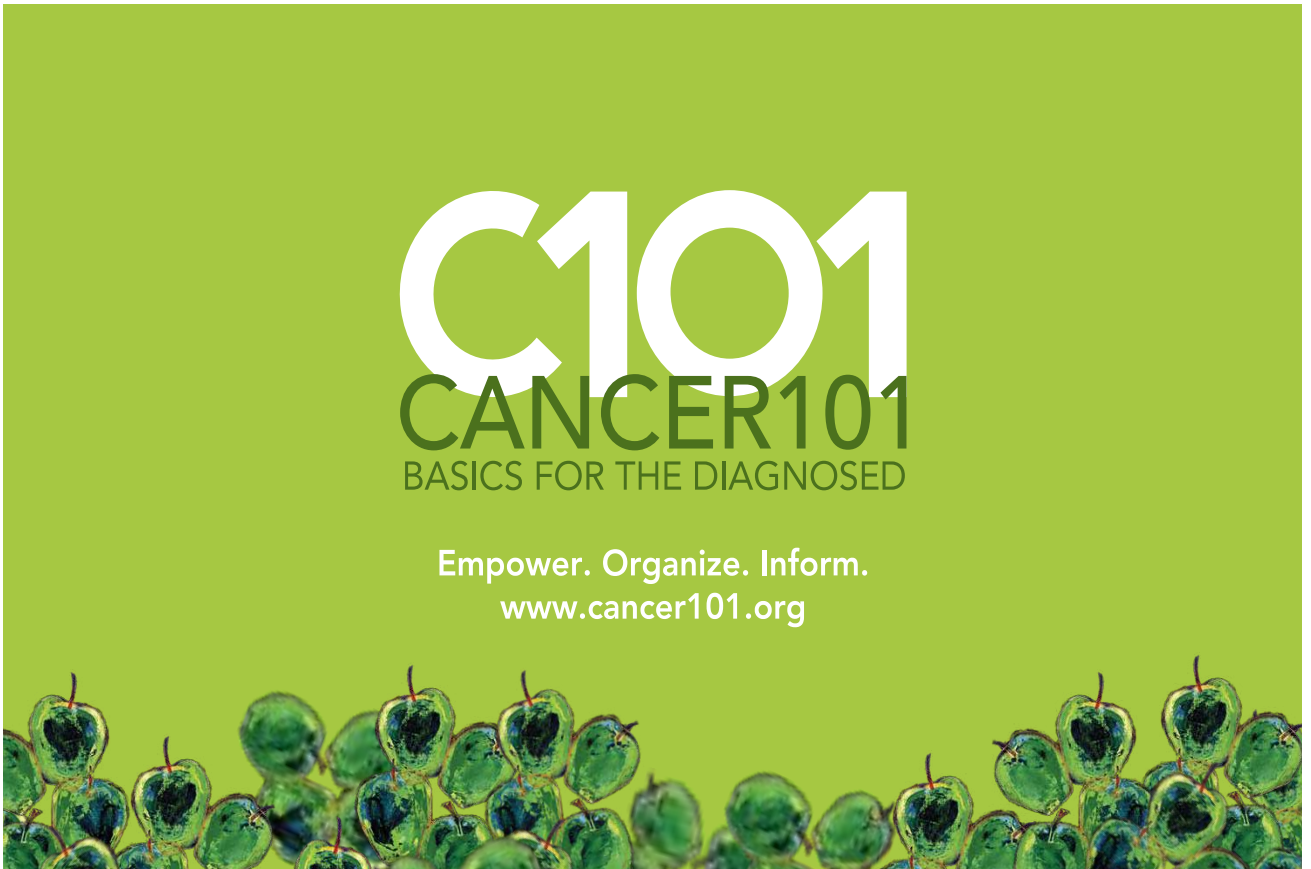


*“The Planner answers virtually every possible question that patients and their loved ones might have. You get so much information that comes your way that the five-pocket folder helps to keep you organized”*

***Robin Roberts, “Good Morning America”***

***Breast Cancer Survivor***



## CANCER101's Mission: Empower-Organize-Inform

To empower, inform and engage cancer patients and their caregivers to take control over their diagnoses and partner with their healthcare team to make informed decisions by navigating the cancer journey.

## CANCER101's Inspiration & Organization Overview

CANCER101 (C101) was founded in 2002 by Monica Knoll, whose experience with being diagnosed with breast cancer in 2000 inspired her to help others. Unfortunately, Monica Knoll lost her battle to ovarian cancer in June 2011, but through her supportive staff, strategic partners, volunteers and board of directors, her legacy and vision lives on through CANCER101.

A cancer diagnosis is often an overwhelmingly frustrating experience. Patients and caregivers are immediately confronted with a deluge of new information, confusing terminology, paperwork, financial concerns and forced to make life-saving (and changing) decisions regarding treatment options. In addition, it's a daunting process to coordinate travel logistics, navigate insurance policies or find help if faced with little or no insurance—all while managing daily work and family obligations. Having a plan of action, the means to stay organized and access to appropriate resources and information is half the battle. C101 meets the cancer patient on the front line and turns a chaotic experience into a calm and organized plan of attack. Just as important, C101 is there after the treatments are over to help survivors manage important post-treatment appointments, medications and survivorship issues.

C101 provides the tools and resources patients and caregivers need to partner with their healthcare team to make informed medical decisions. Participating in the medical plan, instead of being a victim, gives patients and their families a feeling of hope. C101 helps anyone affected by cancer including the newly diagnosed, those with a recurrence, metastatic disease, survivors, caregivers, and healthcare professionals. Our tools are designed to help all demographics including the under-served population. We also consider every recipient of the C101 tools to be a potential foot soldier in educating his/her friends, family & local communities about cancer prevention & early detection.

C101 has distributed resources to over 600 participating National Cancer Institute and Association of Community Cancer Centers, as well as thousands of community oncologist practices, to provide free to patients in need. One of our main objectives includes tailoring our existing resources to meet the needs of various patient demographics. In an era of personalized care, accommodating the needs of patients is critical, thus we intend to evolve through partnerships and collaborations with other organizations to meet those needs.

***“Patients who participate in their fight for recovery along with their healthcare team, rather than acting as hopeless, helpless, passive victims of the illness will improve the quality of their lives and may enhance the possibility of recovery.” - Harold Benjamin, Ph.D., Founder of The Wellness Center Community***

## Program Objectives

1. To provide navigation tools to patients and caregivers, which allow them to make informed medical decisions and create a treatment and maintenance plan in partnership with their healthcare team.
2. To develop a patient engagement platform that helps reduce the healthcare provider: patient communication gap and empowers patients to take an active stance in their healthcare.
3. To engage patients through toolkits that arm them with the opportunity to become part of healthcare team and better manage their disease effectively: A PRESCRIPTION TO LEARN.
4. To promote collaborative decision-making which provides a shared responsibility between patients, caregivers & healthcare team to co-develop a treatment pathway based on the understanding of risks/benefits to achieve an optimal health outcome.
5. To provide a comprehensive guide for patients to handle non-medical issues to help improve quality of life. .
6. To keep patients focused on the tasks associated with a cancer diagnosis, medical history and symptom tracking, adherence to medication, directions and advice as prescribed by the healthcare team.
7. To tailor our resources to meet the needs of varied patient demographics and preferences.
8. To help patients track and manage bills and communications with their insurance companies, doctors and nurses.
9. To educate the community about early detection and prevention and the power of being proactive.

## CANCER101 Navigator

**Description:** The three-ring, tabbed binder includes everything a patient and their caregiver needs to stay organized and informed during their treatment pathway and ten years of follow-up care. Following the first appointment with an oncology specialist, patients leave their cancer center with an essential tool to navigate and become engaged in their cancer journey.

**Partnerships:** Rather than recreate the wheel and create duplicate information, we partner with other credible organizations to disseminate educational resources. The navigator (planner) includes essential information provided by prominent organizations including: National Cancer Institute (NCI), American Society of Clinical Oncology (ASCO) and the Coalition of Cancer Cooperative Groups (CCCG), among others.

**The Navigator's Introduction:** The introduction includes "How to Use This Navigator" and "Four Things You Need to Know" that are translated into Spanish, Chinese, Korean, Russian, Polish, Greek, Japanese, French, and Swahili. This section explains to those with language and cultural barriers that there are services and resources enclosed to help them cope financially and emotionally. Future plans include translation of the navigator into various languages.

**Five-Pocket Folder:** The accordion file is tabbed to store pathology and laboratory reports, test results, prescription and medication instructions, research, insurance paperwork and bills.

### **Tabbed sections include:**

1. **myCANCER101** Tumor specific inserts that provide information developed by NCI. They can be downloaded at [www.cancer101.org/inserts](http://www.cancer101.org/inserts)
2. **Calendar and Appointment Tracker**  
One-year & Ten Year Follow-up Calendar: Track all past/future and follow-up appointments.  
Appointment Tracker: Indicate the status of each appointment and associated test results.  
Address Book and Business Card Holder: Consolidate important information and business cards in one place.
3. **myMedical History:** Detail cancer history including pathology information, test dates and results, treatments, allergies, medications, and family history  
Health Summary Template- **New!**
4. **Understanding the Healthcare System- New!**
5. **Medication & Symptom Tracker:** Record medications and any associated symptoms and severity to allow for accurate reporting to the healthcare team  
Importance of adherence and symptom identification- **New!**
6. **Questions to Ask Your Doctor** by Cancer.Net
7. **What Is a Clinical Trial?** by the Coalition of Cancer Cooperative Groups
8. **Genetics/Personalized Medicine- New!**
9. **Mind, Body & Spirit- Fitness, Nutrition, Beauty & Psychosocial support- New!**
10. **Financial Management- New!**  
Medical Bills and Insurance Tracker: Track all appointments and procedures to help manage incoming bills and insurance claims, Financial Assistance, Managing cost of care
11. **Sexuality & Fertility- New!**
12. **Caregiver Support- New!**
13. **C101 Lifesavers:** A call-to-action to ask patients to teach the cancer community about early detection and prevention.
14. **Medical Dictionary** by National Cancer Institute
15. **Resources:** A vetted list of national resources organized by topic
16. **CANCER101 Partners:** Our generous supporters whose contributions allow for the planner to be made available for free to patients.

## Tumor-Specific Booklets: myCANCER101

**DESCRIPTION:** In partnership with the National Cancer Institute, booklets entitled “What You Need to Know About \_\_\_\_\_ Cancer” are formatted to fit into the C101 navigator depending on cancer type. C101 offers over 22 different cancer booklets for healthcare professionals or patients to insert into the navigators. They can be downloaded at [www.cancer101.org/inserts](http://www.cancer101.org/inserts)

### **EACH BOOKLET OFFERS:**

- General information about their cancer
- Descriptions of medical options, side effects, supportive care, and checkups
- Questions to ask the doctor about cancer and treatment options

### **NCI booklets are offered for the following cancers:**

- |                 |                  |                |                    |              |
|-----------------|------------------|----------------|--------------------|--------------|
| • Bladder       | • Esophageal     | • Leukemia*    | • Multiple Myeloma | • Pancreatic |
| • Brain         | • Hodgkin’s      | • Liver        | • Non-Hodgkin’s    | • Prostate*  |
| • Breast*       | • Lymphoma*      | • Lung*        | • Lymphoma*        | • Stomach    |
| • Cervical*     | • Kidney (Renal) | • Melanoma and | • Oral             | • Thyroid    |
| • Colon/Rectum* | • Larynx         | • Other Skin   | • Ovarian          | • Uterine    |

\*Also offered in Spanish

## Online Navigator Overview (Beta Testing Phase)

The CANCER101 ten-year navigators have been successful through a distribution to over 600 cancer centers and community oncologist practices. We’ve listened to our CANCER101 partners and converted our navigator into an easily accessible and secure site which allows patients to:

- Establish online connections with caregivers, grant calendar access, and set reminders so they can stay up-to-date and offer assistance during the cancer journey
- Document and manage symptoms to share with the medical team
- Organize appointments/ task lists and set text and/or email reminders
- Record all medications and associated adverse events/symptoms.
- Track medical expenses and billing by linking to appointments to alleviate confusion when bills arrive months later

## Target Population and Problems Addressed

- **Newly diagnosed cancer patients:** Patients and caregivers are often overwhelmed by the amount of information and decisions they must make when they are first diagnosed. The navigator is offered to patients when they need it most—when they have their first oncology/surgery appointment.
- **Patients with advanced cancer, metastasis or recurrence:** Patients with advanced cancer, metastasis or recurrence often feel there are not enough resources that meet their needs. C101 has included information that speaks directly to their concerns.
- **Caregivers:** A cancer diagnosis can be overwhelming for the caregiver who must manage a family and their loved-one’s illness. The navigator helps caregivers access information and provides resources and tips to help them cope.
- **Parents of children with cancer:** The navigator helps parents access information and keep everything organized to help fight their child’s cancer.
- **Healthcare professionals:** Many healthcare professionals use the navigator in collaboration with their patients and caregivers. Healthcare professionals tell us that they find that an informed and empowered patient enhances communications and allows for a more successful partnership with their patient in managing their disease.
- **The underserved population including those with language, cultural or financial barriers:** The navigators are written (with the exception of the dictionary) at an 8th grade reading level. The “How to Use” section is translated in 11 languages. Further, the section suggests many ways a healthcare professional can help, including financial support, transportation, and other potential barriers that the underserved population might experience. Future plans include translation of the navigator into other languages.

## CANCER101 in the News

CANCER101 PRESS  
key media from 2004 through the present



[CNN](#)



[Good Morning America](#)



[The Martha Stewart Show](#)



[Big Idea with Donny Deutsch](#)



[NYSE: Ringing The Opening Bell](#)





[Chief Information Officer, Harvard Medical School](#)

## Future Goals

- Expand reach within the community oncologist setting
- Translate the navigator into other languages
- Develop different versions of the navigator to target various stakeholder groups (e.g. Survivors, Young Adult, etc)
- Over 40 countries around the world have contacted C101 to learn how they can offer their patients the C101 navigator. We intend to collaborate with other global partners and reach our international audience.
- Expand CANCER101 to help people with other chronic diseases to include DIABETES101, HYPERTENSION101, AIDS101 and AUTISM101, among others
- Expand our Web site to include City Guides and Calendars of Support for major cities across the country

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