

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

Robin Roberts, “Good Morning America”

ABOUT

CANCER101®



CANCER101's Mission: Empower-Organize-Inform

To empower cancer patients and their caregivers to take control over their diagnoses and engage them as active partners in their care, by arming them with a toolkit to navigate their cancer journey.

CANCER101's Inspiration & Organization Overview

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

A cancer diagnosis is often an overwhelmingly frustrating experience. Patients and caregivers must quickly comprehend new medical information and confusing terminology; make life-saving decisions about treatments, doctors, and cancer centers; and sort through insurance coverage (or search for treatment options without insurance) —all while managing the daily responsibilities of work and family. 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 and local communities about cancer prevention and early detection.

C101 distributes resources to over 350 participating National Cancer Institute and Association of Community Cancer Centers to provide to patients in need. We also plan to expand our reach to the community oncologist setting. 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

Program Objectives

1. To provide navigation tools to patients, caregivers, which allow them to make informed medical decisions and create a treatment and maintenance plan in partnership with their healthcare team.
2. To educate patients and caregivers with resources provided by cancer centers and advocacy organizations eager to help patients with all aspects of their care, including non-medical issues (e.g. finances, childcare, and transportation, etc.).
3. To keep patients focused on the tasks associated with a cancer diagnosis, appointment and medical history tracking, and adherence to medication, directions and advice as prescribed by the healthcare team.
4. To tailor our resources to meet the needs of varied patient demographics and preferences.
5. To help patients track and manage bills and communications with their insurance companies, doctors and nurses.
6. To educate friends, family, and local communities about early detection and prevention.

CANCER101 Navigator (Planner)

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 their cancer journey.

Partnerships: 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 (CCCCG). Patients are now able to download or order a hard copy of tumor-specific information provided by **NCI** to insert into their navigators.

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. Those pages explain to those with language and cultural barriers that there are services and resources inside to help them cope financially and emotionally. Future plans include translating the entire navigator into different languages.

Five-Pocket Folder: The accordion file is tabbed to house pathology reports, research, insurance paperwork, bills, and hospital/ nonprofit information. Inside there is a self-addressed patient survey that provides C101 with essential feedback.

Tabbed sections include:

1. **myCANCER101:** Tumor specific inserts available to patients allowing them to personalize their navigator.
2. **Notes:** Detail important information provided by the healthcare team.
3. **One-year Calendar:** Track all past/future appointments.
4. **Ten-year Follow-up Calendar:** Plot out all follow-up appointments.
5. **Address Book and Business Card Holder:** Consolidate important information and business cards in one place.
6. **Medical History Tracker:** Detail cancer history including pathology information, test dates and results, treatments and medications,
7. **Symptoms Tracker:** Record symptoms and severity to allow for accurate reporting to your healthcare team.
8. **Appointment Tracker:** Indicate the status of each appointment and associated test results.
9. **Medical Bills and Insurance Tracker:** Track all appointments and procedures here to help manage incoming bills and insurance claims.
10. **Questions to Ask Your Doctor:** by Cancer.Net
11. **Cancer Dictionary:** by National Cancer Institute
12. **What Is a Clinical Trial?** by the Coalition of Cancer Cooperative Groups
13. **Advice for the Newly Diagnosed and Their Caregivers:** Practical, non-medical advice from survivors
14. **National Cancer Resources:** A vetted list of resources organized by topic
15. **C101 Lifesavers:** A call-to-action to ask patients to teach their family, friends and local community about early detection and prevention (under development)
16. **CANCER101 Partners**

Cancer-Specific Booklets

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 their navigators.

EACH BOOKLET OFFERS:

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

The CANCER101 ten-year navigators have been successful through a distribution to over 350 National Cancer Institute (NCI) Centers and Association of Community Cancer Centers (ACCC). We’ve listened to our CANCER101 partners and converted our navigator into an easily accessible and secure site which allows you to:

- Establish online connections with caregivers so you can grant them access to your calendar and set reminders so they can stay up-to-date and offer assistance during your cancer journey
- Document and manage symptoms to share with your medical team
- Organize appointments/ task lists and set text and/or email reminders
- Record all medications and appointments online
- 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 are immediately confronted with a deluge of new information, terminology, paperwork, financial concerns and 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. 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. CANCER101 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 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 eighth-grade reading level. The “How to Use” section is translated in eleven languages. It explains the financial and emotional services available to help patients cope, and urges them to find a friend/family member to help them translate important information and resources found inside the navigator. 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. With additional funding, we hope to offer the navigators in other languages.

Surveys Tells Us...



The navigator gives me a sense of control over my diagnosis.	91%
The navigator helps me partner with my doctor to make important decisions regarding treatment options.	89%
I feel better about my prognosis because I am organized to fight my cancer	80%
I have a recurrence/metastatic cancer and I found the resource and support for my needs helpful	90%
If you have visited CANCER101.org's Web site would you recommend it to a friend?	94% yes
I would recommend the C101 navigator to another patient	94%

Future Goals

- Translate the navigator into other languages.
- Over 40 countries around the world have contacted C101 to learn how they can offer their patients a 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, HEARTDISEASE101, AIDS101 and AUTISM101, among others.
- Expand our Web site to include City Guides and Calendars of Support for major cities across the country.

CANCER101 in the News

CANCER101 PRESS
key media from 2004 through the present



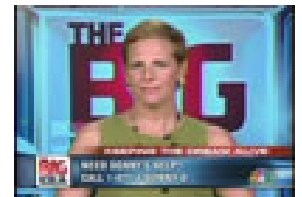
CNN



Good Morning America



The Martha Stewart Show



Big Idea with Donny Deutsch

See more at <http://cancer101.org/press.cfm>.