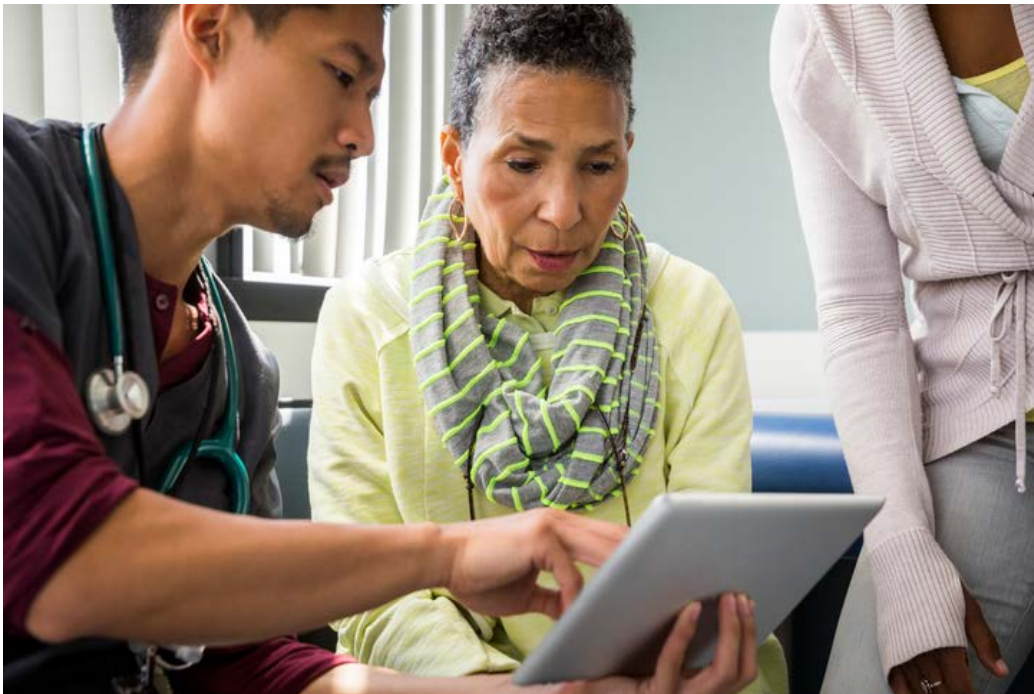


Digital Resource Booklet

NCCN Patient Advocacy Summit:

Better Information for Better Outcomes:
Policy and Practice Strategies
for Patient Education



NCCN Digital Booklet of Patient Advocacy Resources

This booklet includes information from patient advocacy organizations on programs and resources to help connect people facing cancer with reliable health information.

It was developed in conjunction with The National Comprehensive Cancer Network's® (NCCN®) Patient Advocacy Summit: Better Information for Better Outcomes: Policy and Practice Strategies for Patient Education on December 6, 2024.

To view a broader list of advocacy and support groups on the NCCN website, visit [NCCN.org/patients/support-groups](https://www.nccn.org/patients/support-groups).

Contents

- 3 **LUNGeivity Foundation**
- 5 **Latinas Contra Cancer (LCC)**
- 7 **The National LGBTQI+ Cancer Network**
- 8 **Cancer Support Community**
- 10 **Huntsman Cancer Institute at the University of Utah**
- 12 **Collaborative Cancer Care**
- 14 **Tigerlily Foundation**
- 16 **Fight Colorectal Cancer**



LUNGevity Foundation

LUNGevity is the leading nonprofit that's transforming how people are diagnosed and live with lung cancer through research, education, and support. LUNGevity seeks to make an immediate impact on quality of life and survivorship for everyone touched by the disease—while promoting health equity by addressing disparities throughout the care continuum.

Organization URL: www.lungevity.org

Resource or Program Information

LUNGevity Patient Gateways

The LUNGevity Patient Gateways are a central hub of up-to-date information for your specific type of lung cancer. They share tailored resources, tools to find specialists and learn about clinical trials, and timely research updates so you have all the information to live well with your type of lung cancer.

URL: gateway.lungevity.org/

Phone number: 312-407-6100

Email: info@LUNGevity.org

LUNGevity LifeLine Support Program

The LUNGevity LifeLine Support Program matches a lung cancer patient or caregiver with a LifeLine Support Partner. LifeLine Support Partners are lung cancer survivors or co-survivors (family members and caregivers) who have walked the lung cancer path. They volunteer to mentor and offer encouragement, advice, experience, and hope to those newly diagnosed and anyone needing additional support through a one-on-one personal connection by email or telephone. LifeLine Partners can be a vital part of a newly diagnosed patient's

support system and can help navigate through the logistics and emotions of a lung cancer diagnosis. LifeLine matches are made by gender, age group, and similar diagnosis whenever possible.

URL: www.lungevity.org/for-patients-caregivers/support-services/peer-to-peer-mentoring

Phone number: 312-407-6100

Email: info@LUNGevity.org

LUNGeivity Virtual Meetups

LUNGeivity hosts weekly Virtual Meetups for patients, survivors, caregivers, and friends and family members of people with lung cancer to virtually connect face-to-face with others across the country. Whether you are new to your diagnosis or have been navigating the disease for many years, you can find encouragement, valuable information, and true friendship at our Virtual Meetups.

URL: www.lungevity.org/for-patients-caregivers/support-services/virtual-meetups

Phone number: 312-407-6100

Email: info@LUNGeivity.org



Latinas Contra Cancer (LCC)

LCC is creating a more equitable and accessible healthcare system for the Latinx community around issues of cancer.

Organization URL: www.latinascontracancer.org

Resource or Program Information

Patient Navigation and Advocacy

Our Patient Navigation team addresses the critical need for early cancer detection among Latinxs, who face disproportionately lower survival rates. We provide comprehensive support, including translation services, appointment assistance, and access to essential resources. By helping clients navigate the healthcare system and connecting them with necessary support services, we strengthen our community to prioritize their health and improve cancer outcomes.

Phone number: 408-280-0811

Main contact: Maria Zeledon, Patient Advocate Lead, 408-645-5841

Email: maria@latinascontracancer.org

Health Education

Latinas Contra Cancer offers culturally and linguistically tailored education and support, fostering informed decision-making, dispelling myths, and promoting open, judgment-free dialogue. This approach leads to increased early detection, screenings, and testing. Our health education program not only improves access to services that might otherwise go unnoticed, but also helps reduce health disparities with lasting positive impacts.

Phone number: 408-280-0811

Email: office@latinascontracancer.org

Defensoras: Healthcare Advocate Learning Space

Defensoras: Healthcare Advocate Learning Space is a facilitated, collaborative, and interactive advocate space focused on healthcare delivery and payer systems, effective patient advocacy, race and gender-based health disparities, and movement building. Launched in mid-2021, this comprehensive learning space is offered in both English and Spanish, designed as a robust cohort-style experience that equips participants with the knowledge, capacity, and skills necessary to effectively engage with the healthcare system. The learning space is built around 10 core modules that cover essential topics such as patients' rights and healthcare justice. Our goal is to hold space for the power of communities to take charge of their health and to collectively organize as change agents ready to dismantle health inequities in Santa Clara County.

Phone number: 408-280-0811

Email: office@latinascontracancer.org



The National LGBTQI+ Cancer Network

The National LGBT Cancer Network works to improve the lives of LGBT cancer survivors and those at risk by EDUCATING the LGBTQI+ community about our increased cancer risks and the importance of screening and early detection, TRAINING healthcare providers to offer more culturally competent, safe, and welcoming care, and ADVOCATING for LGBT survivors in mainstream cancer organizations, the media, and research.

Organization URL: cancer-network.org

Resource or Program Information

This comprehensive resource guide, developed by the National LGBTQI+ Cancer Network, provides essential materials to advance cancer awareness and health equity in LGBTQI+ communities. The guide includes various co-brandable content, ensuring adaptability for diverse organizations and audiences. It features printable and shareable resources that can be easily accessed at events, providing critical cancer prevention and support information. Unique sharable flyers, co-brandable content, and pamphlets within the guide offer concise, impactful messaging designed to educate and engage audiences quickly. These resources also include toolkits, support group content, and cancer cards containing insights for navigating cancer care within LGBTQI+ populations. Created for ease of use at tabling events, this guide empowers healthcare advocates with the tools needed to foster inclusivity and enhance cancer education.

URL: cancer-network.org/resources/sharable-tabling-resources/

Phone number: (212) 675-2633

Email: Info@cancer-network.org



Cancer Support Community

Organization Description: Cancer Support Community is a global non-profit network of 196 locations, including CSC and Gilda's Club centers, hospital and clinic partnerships, and satellite locations that deliver more than \$50 million in free support and navigation services to patients and families. Our mission is to uplift and strengthen people impacted by cancer by providing support, fostering compassionate communities, and breaking down barriers to care.

Organization URL: www.cancersupportcommunity.org/

Resource or Program Information

Tips for Managing and Budgeting Your Cancer Costs

When you or a loved one has cancer, you are focused on the disease, treatment, and doctors. Many people forget to ask questions that can help them to manage the costs associated with facing cancer—important questions like “How much will this cost?” and “How can I manage the costs?” The Cancer Support Community (CSC) has prepared this helpful booklet to help you understand the financial aspects of a cancer diagnosis. There will be many physicians and health centers involved in your care. While they will work together for you, they each will bill you separately. It can get confusing. We hope that this booklet will

help you learn more about your options, know what questions to ask, and take control of your treatment and costs.

URL: www.cancersupportcommunity.org/help-managing-cancer-costs

Phone number: 888-793-9355

Email: contacthelpline@cancersupportcommunity.org

Cancer Support Helpline

Our Cancer Support Helpline is staffed by community navigators and resource specialists who have extensive experience in helping people affected by cancer. We provide guidance, resources, and support to cancer patients or their loved ones with a variety of needs – from getting information about cancer, identifying a local support group, or just finding someone who is willing to listen. So that no one faces cancer alone. Our services include:

- Connecting callers to local or national resources, counseling, support groups, treatment lodging & transportation services, and other programs
- Live web chat option for those who prefer not to call – Find the Chat Now window at the bottom of your screen
- Specialized information and navigation in finances & treatment costs, clinical trials, pediatric oncology, CAR T cell therapy, and genetics/genomics
- Treatment decision-making education
- Access to an online distress screening program, CancerSupportSource®
- Guidance on the full scope of resources at the Cancer Support Community
- Live, bilingual Spanish navigation services
- Over-the-phone translation support in over 200 languages

URL: www.cancersupportcommunity.org/cancer-support-helpline

Phone number: 888-793-9355

Email: contacthelpline@cancersupportcommunity.org



Huntsman Cancer Institute at the University of Utah

Huntsman Cancer Institute at the University of Utah is the National Cancer Institute-designated Comprehensive Cancer Center for Utah, Idaho, Montana, Nevada, and Wyoming. With a legacy of innovative cancer research, groundbreaking discoveries, and world-class patient care, we are transforming the way cancer is understood, prevented, diagnosed, treated, and survived.

Organization URL: healthcare.utah.edu/huntsmancancerinstitute/

Resource or Program Information

American Indian, Spanish-speaking, and Frontier/Rural Patient Navigation

It can be hard for cancer patients to find their way through the healthcare system. Patient navigator services at Huntsman Cancer Institute can help. All patient navigator services are free. Navigators can make sure patients, caregivers, and doctors understand each other and get needed services. Patient navigators help in many ways, including providing information about what to expect; coordinating appointments; establishing and helping maintain communication between the patient and health care team; arranging interpreters for appointments, referring to community support services; and locating financial support and helping complete forms.

Specialized navigators are available to support our American Indian, Spanish-speaking, and Frontier/Rural patients and caregivers. For information on each program visit link below.

URL: healthcare.utah.edu/huntsmancancerinstitute/wellness-support/patient-navigators

Phone number: 801-646-4254

Email: navigation@hci.utah.edu

Adolescent and Young Adult Patient Navigation

Description (200 words): The Huntsman-Intermountain Adolescent and Young Adult (HIAYA) Cancer Care Program serves adolescents and young adults (AYAs) between 15 and 39 years old who have been diagnosed with cancer. A cancer diagnosis presents different challenges for AYAs. Cancer can disrupt big milestones that commonly happened during this age range like completing school, choosing a career path, building personal relationships, and working toward emotional, social, and financial independence.

HIAYA seeks to address the unique needs of AYAs in Utah and the surrounding states. We currently offer: AYA patient navigators to help guide young people through their cancer care, social media connection on Facebook, X, and Instagram, a community resource packet, and a seasonal newsletter.

URL: healthcare.utah.edu/huntsmancancerinstitute/wellness-support/patient-navigators/adolescent-young-adult

Phone number: 801-646-4254

Email: navigation@hci.utah.edu

Cancer Learning Center

The G. Mitchell Morris Cancer Learning Center (CLC) is your source for free cancer information about many cancer topics, including the following: types of cancer, treatment and side effects, clinical trials, coping, caregiving, integrative health, financial resources, and many others. We have a lending library containing over 2,000 cancer related books, audios, and videos.

Our staff are trained cancer information specialists. We all have degrees in health education, public health, or another related field. We can answer questions in person, over the phone, and via e-mail, text, and live chat. We are happy to help you find the information you need. Our staff guide you through some important first steps and questions you might want to ask at your appointments. We are here to empower you to navigate the system so you can fully participate in decisions about your health.

URL: huntsmancancer.org/clc

Phone number: 1-888-424-2100

Email: cancerinfo@hci.utah.edu



Collaborative Cancer Care

Collaborative Cancer Care mental health practice dedicated to supporting cancer patients, survivors, and caregivers through personalized counseling, medication management, education, advocacy, and healthcare navigation.

Organization URL: www.collaborativecancercare.com

Resource or Program Information

13 Questions to Ask When Your Loved One is Diagnosed with Cancer

This essential resource provides caregivers and family members with 13 insightful questions to help guide discussions with healthcare providers when a loved one faces a cancer diagnosis. Designed to empower you with clarity and confidence, these questions cover topics from treatment options and side effects to mental health support and lifestyle adjustments. Use this guide to ensure you and your loved one are

informed and supported every step of the way.

URL: collaborativecancercare.com/13questions/

Phone number: 860-351-6818

Email: info@collaborativecancercare.com

The 5-Step STOPP Method for Stress Management

The STOPP Method is a powerful, practical tool to help you manage stress by using intentional pauses to regain control in challenging moments. This simple, step-by-step approach guides you through grounding yourself, assessing the situation calmly, and making thoughtful choices. Use this method anytime stress arises to build resilience, clarity, and a stronger sense of calm.

URL: collaborativecancercare.com/stopp-method/

Phone number: 860-351-6818

Email: info@collaborativecancercare.com

Café Conversations

Description (200 words): Join us each month for our Cafe Conversations—a warm, inclusive gathering designed to foster open dialogue and community around emotional well-being. Each session, we focus on different themes related to stress management, emotional intelligence, self-care, and life. Whether you're a cancer patient, caregiver, healthcare professional, or anyone looking to enhance their well-being, our conversations provide valuable insights, practical tools, and a supportive space to share experiences. Grab your favorite drink and connect with others in a casual setting as we navigate the journey to better mental health together.

URL: collaborativecancercare.com/cafeconversations/

Phone number: 860-351-6818

Email: info@collaborativecancercare.com



Tigerlily
Foundation
Beauty. Strength. Transformation.

Tigerlily Foundation

Tigerlily Foundation is a national women's health and oncology organization providing education, awareness, advocacy and hands-on support to young women (15-50) before, during and after cancer.

Through our programs, we seek to educate and empower women of all backgrounds, including those at heightened risk, those facing health disparities, and those with less access to care. We strive to improve the quality of life and end isolation among cancer survivors, patients and those living with metastatic cancer.

Organization URL: www.tigerlilyfoundation.org

Resource or Program Information

ANGEL (Advocate Now to Grow, Empower and Lead) Advocacy Program

Have you been affected by breast cancer, either as a patient, a caregiver, or an ally? Through the ANGEL Advocacy Program, Tigerlily Foundation offers free comprehensive virtual training for Women of Color between the ages of 21-50, that will teach you how to advocate for yourself and/or your loved ones. Tigerlily's ANGEL Advocates have found a supportive community through this virtual training program where you will gain the knowledge and tools to effectively manage a cancer experience, make informed decisions, and advocate for yourself and others.

Many ANGEL Advocates are directly involved with developing our programs and partnering with research and scientific communities to ensure clinical trials, studies, programs, and content are relevant to their population.

Tigerlily's ANGEL Advocates are at the forefront of the charge to transform health outcomes for Black and Brown women, dismantle disparities, and achieve health equity for all. ANGELs inform decision makers on how they are educated and represented within the patient, policymaking, provider, research and scientific communities. We work with patients and stakeholders in communities with the highest breast cancer death rates for Black and Brown women. Don't wait—contact us to join the ANGEL community today.

URL: angel.tigerlilyfoundation.org/

Phone number: 888-580-6253

Email: TLFANGEL@tigerlilyfoundation.org

Tigerlily Foundation's BREATHE Tv

Tigerlily Foundation's BREATHE Tv is a sacred space, an educational and inspirational cancer video program that brings together patients, providers and loved ones in a space of purpose, while engaging in authentic and meaningful conversations about cancer, women's health, and lifestyle. BREATHE Tv is in its 5th season and over the years has reached millions of new viewers year after year becoming a celebrated program for Tigerlily Foundation.

URL: breathetv.tigerlilyfoundation.org/

Phone number: 888-580-6253

Email: info@tigerlilyfoundation.org

MY LIFE (Metastatic Young, Living In Focus, Empowered)

MY LIFE Matters Magazine is a digital and print magazine collaboration with Tigerlily Foundation & Elephants and Tea. Each magazine takes a heart centered look at important topics that impact the cancer community with the perspectives and highlights from individuals living with metastatic or stage IV cancer as well as individuals diagnosed with early-stage cancer. The magazine is educational, supportive, and intentional. Articles are written by Survivors, Thrivers, medical experts, patient advocates and caregivers. Sharable's, tips, infographics and educational tools are also provided in the magazine.

#MyLifelsMyLegacy video series by Tigerlily Foundation is a collection of intimate vignettes

showing the lives and living legacy of remarkable individuals. Personal stories of people living with Stage IV cancer, early-stage cancer in addition to medical experts, industry trailblazers, caregivers who have not been diagnosed with cancer. These stories build a bridge of knowledge, love, faith, hope and transformation that help us understand the impacts of cancer and provide guidance that will help generations to come.

URL: mylife.tigerlilyfoundation.org/

Phone number: 888-580-6253

Email: info@tigerlilyfoundation.org

Tigerlily's HEAL Policy Center of Excellence

Tigerlily's HEAL Policy COE educates, empowers, and lifts patient voices to ensure they are amplified, to lead systemic changes through policy at the local, state, and federal level. These efforts are focused on ending barriers to accessing and receiving quality, equitable care for all; leading innovation through patient-leadership; and achieving health equity and eliminating disparities in cancer.

URL: heal.tigerlilyfoundation.org/

Phone number: 888-580-6253

Email: heal@tigerlilyfoundation.org



Fight Colorectal Cancer

Fight Colorectal Cancer (Fight CRC) is a leading advocacy organization dedicated to empowering patients and raising awareness about colorectal cancer. They provide comprehensive resources, support, and education to those affected by the disease.

Organization URL: fightcolorectalcancer.org/

Resource or Program Information

Your Guide in the Fight

Your Guide in the Fight™ is a comprehensive resource developed by Fight Colorectal Cancer to support individuals at every stage of their colorectal cancer journey. This guide offers detailed information on diagnosis, treatment options, and survivorship, empowering patients with the knowledge needed to make informed decisions. Additionally, it provides access to a supportive community through online meetups, connecting patients, survivors, and caregivers for shared experiences and peer support. The guide also includes practical tools and checklists to assist in managing appointments, treatments,

and communication with healthcare providers. By offering both educational content and emotional support, “Your Guide in the Fight” serves as an essential companion for those navigating the complexities of colorectal cancer.

URL: fightcolorectalcancer.org/resources/your-guide-in-the-fight/

Phone number: (877) 427-2111

Email: info@fightcrc.org

Clinical Trial Finder

The Clinical Trial Finder is an innovative tool provided by Fight Colorectal Cancer to assist patients in locating and understanding clinical trials relevant to colorectal cancer. This resource offers a curated list of high-impact research studies, focusing on metastatic, stage IV patients with both microsatellite stable (MSS) and microsatellite instability-high (MSI-H) statuses. By simplifying the search process, the Clinical Trial Finder enables patients and their healthcare teams to explore potential treatment options that may not be widely available. The tool is designed to be user-friendly, providing detailed information about each trial, including eligibility criteria, study locations, and contact information. By facilitating access to cutting-edge research, the Clinical Trial Finder empowers patients to make informed decisions about their treatment pathways and contributes to advancing colorectal cancer research.

URL: fightcolorectalcancer.org/resources/clinical-trial-finder/

Phone number: (877) 427-2111

Email: info@fightcrc.org



For more information on the NCCN Oncology Policy Program,
please visit [NCCN.org/policy](https://www.nccn.org/policy) or contact:

Aaron Bailey, MPP
Policy Specialist
bailey@nccn.org