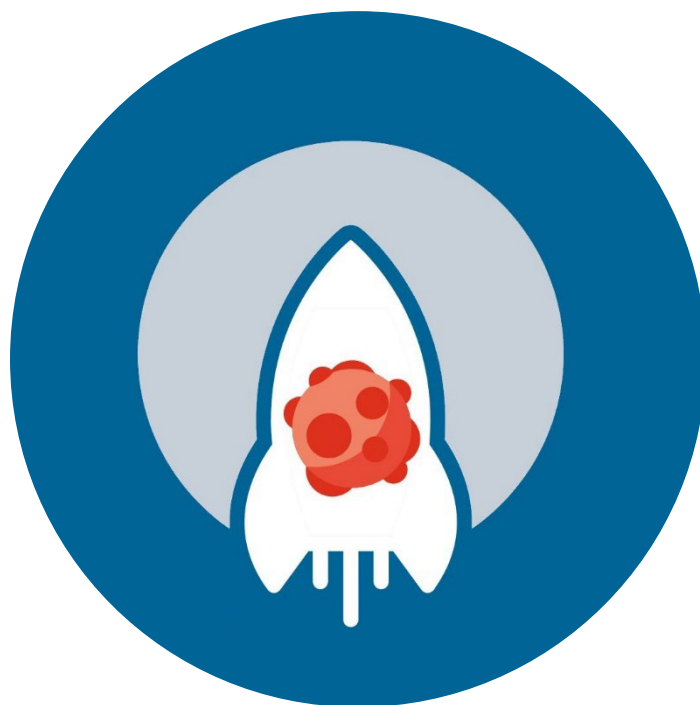


Cancer Moonshot



A Series by:

Real World Health Care

2024

The Cancer Moonshot seeks to mobilize a national effort to end cancer as we know it by accelerating scientific discovery in cancer research, fostering greater collaboration and improving the sharing of cancer data.

Cancer Moonshot is a recently published series of articles that celebrates the efforts and achievements of organizations committed to making a positive impact on people living with cancer by participating in this national effort.

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Contents

Engaging the LGBTQ+ Community in Tobacco Cessation	3
<i>National LGBT Cancer Network</i>	
Colorectal Cancer Alliance Offers Support Hub for Patients, Survivors & Caregivers	6
<i>Colorectal Cancer Alliance</i>	
Expanding Access to Leukemia & Lymphoma Care.....	9
<i>Leukemia & Lymphoma Society</i>	
American Cancer Society: Patient Navigation Improves Cancer Care Outcomes.....	12
<i>American Cancer Society</i>	
Unique Partnership Expands Access to Oncology Clinical Trial Patients	16
<i>Family Reach</i>	
Early Detection Program Seeks to Improve Compliance with Recommended Cancer Screenings	18
<i>Prevent Cancer Foundation</i>	
Providing Support to Patients and Families as They Navigate a Cancer Diagnosis	22
<i>Cancer Support Community</i>	
HealthWell Foundation Launches Oncology Caregiver Behavioral Health Fund	25

Engaging the LGBTQ+ Community in Tobacco Cessation

In September 2023, the Biden-Harris Administration announced a series of initiatives being undertaken by non-profit organizations to deliver on the promise of the White House Cancer Moonshot: to end cancer as we know it. One of those initiatives is a campaign to make tobacco cessation education materials more readily available to LGBTQ+ communities, an effort spearheaded by the [National LGBT Cancer Network](#).

Building on its community-tailored website and a series of social media shareables, the National LGBT Cancer Network will create a series of LGBTQ+ tailored tobacco cessation materials and will launch a print-on-demand store for the materials. They will work with stakeholders like the North American Quitline Consortium, NCI-Designated Cancer Centers, and community members to ensure the materials are compelling and motivational and will widely promote their availability.

Tobacco: The Winner of a Gruesome Race

According to National LGBT Cancer Network Executive Director, Scout, PhD, LGBTQ+ communities use commercial tobacco products (including combustible and alternative products) at rates 49 percent higher than the general population. LGBTQ+ youth are especially vulnerable to the lure of tobacco; many use it as a bad coping mechanism for the discrimination they face in their daily lives.

"When compared to other health conditions like mental health issues or even HIV, tobacco is one of the biggest factors that takes years off the lives of LGBTQ+ communities," Dr. Scout says. "It is the unlikely winner of a gruesome race."



Dr. Scout

Prior to last September's announcement from the White House, Dr. Scout says he was encouraged to learn that the relaunched Cancer Moonshot program would seek to include the voices and expertise of diverse populations from the outset. He notes that LGBTQ+ communities are particularly underserved populations in the larger universe of those facing health disparities.

"Eliminating disparities in cancer risks, detection, and treatment will help to significantly reduce the impact of the disease," he says. "However, health disparities are not created with a one-size-fits-all approach, and they can't be eliminated that way."

To that end, the National LGBT Cancer Network focuses heavily on educating its communities about the pernicious effects of [tobacco industry marketing](#) designed to keep them "hooked" on their products. For example, LGBTQ+ people are three times more likely to be exposed to tobacco coupon messages on video streaming websites, and menthol tobacco products are heavily marketed to LGBTQ+ communities. In part because of these marketing activities, LGBTQ+ adults spend over \$2.6 billion on cigarettes every year.

One way the Network is educating LGBTQ+ communities is through its [Out Proud Free](#) campaign, which aims to ensure that tobacco industry marketing and “myths” don’t unduly influence behavior.

“We see lots of tobacco flavors that appeal to young queer folks, like cotton candy and cherry starburst,” says Dr. Scout. “We need our communities to be aware that product ‘tricks’ like these are creating an addiction they will be fighting for decades.”

Mistrust Affects Access to Care

Dr. Scout notes that LGBTQ+ communities tend to mistrust both the medical system and programs from government bodies like state departments of health – especially considering the recent surge in anti-transgender legislation across the country. They are therefore less likely to be aware of tobacco cessation resources and quit lines, feel less welcome by them, and less likely to use them.

“When reaching out to a tobacco quit line or other smoking cessation services, it’s incredibly difficult to talk about the stressors and triggers that may lead you to smoke while also trying to hide a huge portion of your life,” he says. “It is critical that these programs provide a space and approach through which we can see ourselves represented.”

To address this issue, The Network created [OutLast Tobacco](#), an online portal designed to help smoking cessation service providers create a safe and welcoming space for LGBTQ+ individuals and help them increase their use of quit line services. It also works directly with various quit lines, providing expert training around how to be more welcoming, engaging, and offer more tailored advice to LGBTQ+ callers.

The National LGBT Cancer Network is also home to the CDC-funded [Tobacco Related Cancer Project](#), which aims to reduce tobacco and cancer-related disparities in LGBTQ+ populations by:

- Administering a national network of partners, including CDC-funded tobacco and cancer programs, national organizations, and state and local departments of health
- Providing training and technical assistance to network members and CDC grantees
- Increasing the reach of national, state, tribal, territorial, and local interventions
- Increasing the reach of mass health communications through tailored messaging

As an example of this effort, the Network helped New York State create its first queer-focused smoking cessation advertising campaign, providing relevant evidence to support the campaign, and working with creative designers to tailor the ads for the most effective impact.

The Network’s training and technical assistance services are not limited to tobacco-related health concerns. Its [Welcoming Spaces](#) program, developed in collaboration with the Society for Gynecologic Oncology, provides LGBTQ+ Cultural Humility training for health care professionals. The free program, available for continuing education credits, consists of eight online modules, each of which are 45 minutes long and can be viewed on demand.

"If providers are interested in doing a better job caring for their LGBTQ+ patients, they don't have to wait for training to come to them. They can use this to up their game," Dr. Scout says.

Importantly, the LGBT Cancer Network also provides its own welcoming spaces for LGBTQ+ cancer patients, through free online [peer-support groups](#) and a list of [welcoming cancer screening and treatment professionals](#).

"Lack of social support is one of the top problems facing LGBTQ+ cancer patients and survivors," Dr. Scout concludes. "We are honored to provide these services to offer a baseline of support for queer people who are facing this difficult life challenge."

Colorectal Cancer Alliance Offers Support Hub for Patients, Survivors & Caregivers

Throughout 2024, *Real World Health Care* will be shining a spotlight on non-profit organizations that are working to end cancer as we know it by participating in the Cancer Moonshot Initiative coordinated through the White House. In this Colorectal Cancer Awareness Month edition, we focus on the Colorectal Cancer Alliance, the nation's leading non-profit dedicated to colorectal cancer.

We spoke with Marianne Pearson, Senior Director of Patient Navigation, about how the Alliance is supporting patients with its programs and services – including its BlueHQ support hub recently recognized by Cancer Moonshot Initiative – as well as the Alliance's plans for Colorectal Cancer Awareness Month.

Cancer Moonshot Addresses Common Goals

Real World Health Care: How did the Colorectal Cancer Alliance get involved in the White House's Cancer Moonshot initiative? How does Cancer Moonshot align with the Alliance's goals?

Marianne Pearson: The Alliance has always been a proponent of the White House Cancer Moonshot Initiative because we hope to achieve the same goal of reducing cancer deaths. We're further aligned on the goals of advocating for prevention, creating access and proper care, magnifying support, and accelerating research to eradicate cancer.



Marianne Pearson

We were honored to be recognized by the White House last year for launching BlueHQ, a comprehensive support hub for colorectal cancer patients, survivors, and caregivers. In addition, last March, at the White House Cancer Moonshot Colorectal Cancer Forum, Alliance CEO, Michael Sapienza, participated in the Colorectal Cancer Screening and Prevention Panel to emphasize that colorectal cancer is one of the most preventable cancers with timely screening. More recently, we launched Project Cure CRC, an initiative to invest tens of millions of dollars in colorectal cancer research over the next two years to accelerate our mission of ending the disease in our lifetime.

Personalized Colorectal Cancer Resources

RWHC: How does BlueHQ work?

MP: BlueHQ is an all-inclusive colorectal cancer support hub with personalized resources, tools, and communities for patients and caregivers. It helps patients and caregivers navigate treatment and survivorship, connect with people who understand, and find the right information. It is the best way to learn, connect, and take action to improve colorectal cancer outcomes. I would like to highlight several key elements of the program.

- **Resources:** BlueHQ suggests helpful information and resources that align with a patient's exact profile, including a clinical trial finder.

- Community: BlueHQ connects patients with thousands of allies with similar experiences. It helps patients and caregivers find a community—the people who understand.
- Notes: Patients and caregivers can safely and securely store notes from appointments, track things at home, or use BlueHQ as a private journal. It offers the ability to look back (sorting by type of info or date) or share notes history with caregivers or a medical team.

Colorectal Cancer Screening and Prevention

RWHC: What are other things the Alliance is doing to address the spirit of the Cancer Moonshot?

MP: Our screening and prevention care programs focus on preventing colorectal cancer and identifying cancer at as early a stage as possible by early screening mechanisms. We have low-cost or no-cost screening navigation that helps streamline and reduce barriers to care by providing colonoscopies or in-home kits for free or at low cost to the community.

We also have relationships with other non-profits and industry partners who support and focus on prevention in communities most at risk, thus providing more resources and support to reduce the barriers to patients receiving screenings.

Colorectal Cancer Awareness Month

RWHC: How can people engage with the Alliance and the colorectal cancer community during Colorectal Cancer Awareness Month?

MP: This March marks an important milestone for the Colorectal Cancer Alliance as we celebrate our 25th anniversary of positive impact on March 18. We plan to recognize this important date in our March efforts and throughout the year.

During National Colorectal Cancer Awareness Month in March, we have several initiatives planned to help spread awareness and education about the disease. We will be promoting prevention and screening awareness through traditional and social media outreach, encouraging people to learn more about risk factors, symptoms, and screening options at quiz.getscreened.org, where they can take an easy quiz that provides a personalized screening recommendation. We will also encourage patients and caregivers to visit colorectalcaner.org and BlueHQ.org for colorectal cancer resources and support.

Another significant effort we are working on for March is the Alliance's largest awareness and fundraising walk event of the year, ScopeItOut. This year's ScopeItOut will take place on Sunday, March 24, at the National Mall in Washington, D.C. There will also be a Coast-to-Coast ScopeItOut, which is a live, virtual broadcast of the event, so that anyone across the nation can participate in this walk to end colorectal cancer. To learn more and register visit www.scopeitout.org

Patient-Centered Programs

RWHC: What are some other Alliance programs and services you would like to highlight?

MP: We focus our cancer care programs on the top identified concerns of patients and families going through cancer such as financial, emotional, social, and access to

care/barriers to care. We tailor our programs and support to meet the individual needs of those who contact the Alliance via our helpline, online communities, or by direct referral.

A few highlights include:

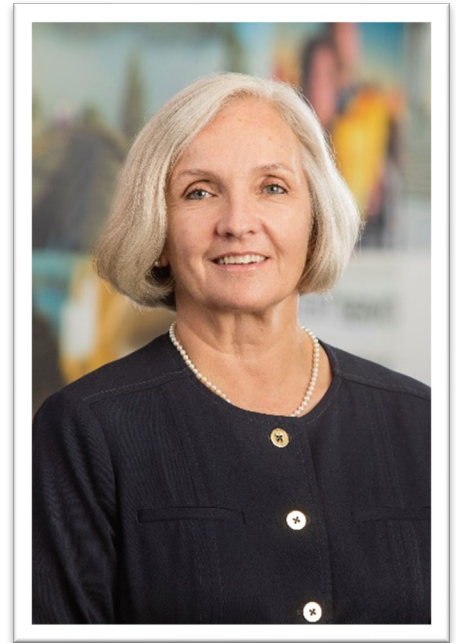
- **LIVE NAVIGATION:** The Alliance provides free access to a team of certified patient and family support navigators. People can connect with them on our toll-free Helpline at (877) 422-2030 and via our web chats.
- **BUDDY PROGRAM:** No one should face colorectal cancer alone, and our Buddy Program makes sure no one must. The Alliance hand-matches patients and caregivers with a buddy who has had similar experiences.
- **ONLINE CHATS:** An easy way to connect with others who share similar experiences is in our online chat room.
- **BLUE HOPE NATION:** Blue Hope Nation is the Alliance's Facebook support group, where users share stories, ask for insight, and provide tips based on their experiences.
- **FINANCIAL ASSISTANCE PROGRAM:** The Alliance's Blue Hope Treatment Awards Program provides eligible patients with a one-time \$200 check to help with daily expenses that add to their burden during treatment.
- **RESOURCE GUIDES:** The Alliance's frequently updated Support and Financial Resource Guide is an extensive collection of helpful resources and organizations for those experiencing colorectal cancer.
- **COLORECTAL CANCER ALLIANCE CLINICAL TRIAL FINDER:** Clinical trials let patients tap into promising new therapies while being closely monitored by doctors. The Alliance's colorectal cancer clinical trial finder tool offers a personalized list of trials based on a patient's inputs. It also guides users through the search and enrollment process.
- **PERSONALIZED TREATMENT PROGRAM:** This program provides personalized treatment options to patients, giving stage III and IV patients access to the most effective treatment options and experts to help with planning — all at no cost.
- **AllyCon:** AllyCon is the Alliance's national conference for patients, survivors, caregivers, and family members to connect. AllyCon welcomes experts from across the cancer care continuum to provide allies with the latest updates in treatments, research, and tips to make the cancer journey a little easier.

Expanding Access to Leukemia & Lymphoma Care

This year, *Real World Health Care* is highlighting non-profit organizations recognized by the Biden administration's Cancer Moonshot program. In this edition, we feature the Leukemia & Lymphoma Society (LLS), the largest non-profit dedicated to creating a world without blood cancers. Since 1949, LLS has invested more than \$1.7 billion in groundbreaking research, pioneering many of today's most innovative treatment approaches for leukemia, lymphoma, Hodgkin's disease, and myeloma.

LLS was recognized by the White House Cancer Moonshot for its \$17+ million investment and efforts to promote health equity by bringing clinical trials and treatment innovation to diverse and underrepresented communities.

"The Cancer Moonshot and LLS have a joint mission to accelerate science and collaborate in the collection and sharing of data to help ensure that health policies are purposeful and effective," says Gwen Nichols, MD, Executive Vice President & Chief Medical Officer, LLS. "LLS brings a unique perspective to this goal due to our experience in research, clinical trials, patient assistance, patient and professional education, and public policy advocacy."



Gwen Nichols

IMPACT Program to Bring Clinical Trials to More Patients

One of the LLS programs highlighted by the Cancer Moonshot program is its Influential Medicine Providing Access to Clinical Trials (IMPACT) Research Grant program. The goal of the program is to expand clinical trial access by opening trials to patients being cared for in community oncology centers. Traditionally, clinical trials are held predominantly at large, academic medical centers, often in major metropolitan areas.

"In the cancer world, access to clinical trials can sometimes mean the difference between life and death," says Dr. Nichols. "Unfortunately, for many cancer patients, such access is extremely limited or completely unavailable."

Dr. Nichols points to several factors that affect clinical trial access, some of which are cost-related, like the ability to afford adequate health insurance. Living in a rural area can also impede access to clinical trials. Costs related to gas, vehicle wear-and-tear, lodging, and parking can add up, and the time commitment for regular and frequent visits to trial locations in major cities can be difficult for working patients and their caregivers.

"Even if you consider someone living in an outer borough of New York City, getting into midtown Manhattan for regular appointments can mean a couple hours of bus, subway, and taxi time," she says. "Only the most motivated, and often well-to-do, patients can commit to the time and expense required."

People of color and those for whom English is a second language also face barriers to clinical trial access, Dr. Nichols says, noting that the nation's history of race-based health inequities has led to a high level of mistrust in the medical field among underserved communities. She says the LLS is working to engage these communities to help them understand that clinical trials may be the best way for them to get access to therapies they may otherwise not be able to get or afford.

The IMPACT program funds health care infrastructure that uses a hub-and-spoke approach in which major cancer centers lead the trials and local cancer centers recruit patients and deliver trial-related care, including routine labs, bloodwork, and physical exams. Dr. Nichols says the IMPACT model is most appropriate for later-phase trials in which treatment efficacy is being tested instead of earlier-phase trials testing treatment safety.

Recipients of LLS's IMPACT grant recipients include:

- City of Hope, Duarte, California, and local oncology centers covering 9,365 square miles in southern California serving a multi-racial, multi-ethnic community of 17 million people.
- Weill Cornell Medical Center, New York City, and local clinics throughout Queens and Brooklyn, where community physicians and oncologists will receive education and training designed to increase patient enrollment in trials.
- MD Anderson Cancer Center and local oncology centers in south Texas serving communities with high numbers of Hispanic and Black patients.
- Emory University, Atlanta, and community sites serving inner-city Atlanta and rural Georgia.
- Mayo Clinic, Rochester, Minnesota, and 35 local oncology centers serving patients throughout rural, underserved communities in Minnesota, Wisconsin, and Iowa, as well as metropolitan Minneapolis.
- University of Colorado, Denver, and local oncology centers throughout Colorado and the Rocky Mountain Region, including those serving Native American patients.
- Vanderbilt University Medical Center, Nashville, and nine local oncology centers in the Delta Regional Authority, home to some of the highest cancer rates in the U.S.

"With the right infrastructure in place, this hub-and-spoke model will allow patients to receive care from a known and trusted local provider and help that local provider maintain their connection with their patient instead of referring them elsewhere," Dr. Nichols says.

Equity in Access Research Program Seeks to Reduce Barriers to Care

The White House Cancer Moonshot also recognized LLS's Equity in Access Research Program, which aims to generate new evidence that can guide policy reform and changes in health care practice, to help reduce barriers to care by mitigating the impact of social, economic, and environmental disadvantages.

The program invites applications from researchers in two areas:

- Building evidence for effective strategies to increase therapeutic cancer clinical trial accrual, focusing on promoting access for patients in underrepresented groups.
- Understanding how health insurance affects equity in access to care for patients with and survivors of blood cancer.

“While there has been a wealth of research programs studying the problem of access, very few have studied potential policy solutions,” Dr. Nichols says. “We want to fund research that digs deeper into nuances within populations and develops plans for implementing solutions that have a demonstrable effect on health outcomes.”

As an example of the type of research funded by the program, Dr. Nichols points to a 2023 program grant that funds a team of investigators studying how increased cost-sharing for cancer care affects patient outcomes and financial security, which pose high financial risk to working-aged adults undergoing treatment for blood cancer. The goal of the research is to inform the development of policy-relevant solutions related to benefit design in individuals with blood cancer, including state and federal policies governing insurance regulations.

Another previous grantee studied Medicare plan selection – a complex process with many different options – comparing beneficiaries with and without a history of cancer. The research found that individuals with a history of cancer select plans with greater financial protections and broader health care provider networks than those without a history of cancer. The researchers concluded that it is imperative to improve educational resources that help beneficiaries understand their coverage options and select a plan that best meets their current and future health care needs.

Support for Clinical Trial Participants

Beyond funding research and initiatives to expand access to clinical trials, LLS offers a Clinical Trial Support Center with free resources and support to help patients decide whether the choice to join a clinical trial is right for them. For example, LLS Clinical Trial Nurse Navigators can help patients by conducting comprehensive clinical trial searches and personally assisting them and their caregivers throughout the entire clinical trial process. LLS Information Specialists offer guidance through cancer treatment and related financial and social challenges, as well as provide accurate, up-to-date disease, treatment, and support information. LLS Registered Dietitians provide patients and their caregivers with free nutrition consultations by phone or email.

“These unique services are designed to help remove the hurdles that get in the way, even for patients who are highly motivated to participate in a clinical trial,” concludes Dr. Nichols. “They also help patients who may be curious about available clinical trials, even if they don’t take advantage of those opportunities immediately.”

American Cancer Society: Patient Navigation Improves Cancer Care Outcomes

As part of our ongoing coverage of non-profit organizations with programs and initiatives aligned with the White House Cancer Moonshot, *Real World Health Care* turns our spotlight to the American Cancer Society (ACS) and two of their initiatives focused on improving patient navigation. For more than 30 years, ACS has been a leader in establishing patient navigation as a path to ensuring access to quality care across the cancer continuum.

Patient navigation is one of the only evidence-based interventions to eliminate health disparities and improve health equity in cancer care.¹ Patient navigators help guide patients through the often-complicated health care systems with the resources they need to get care. Navigation is a crucial component of cancer care, from prevention through treatment and survivorship. By providing individualized assistance to patients, families, and caregivers, navigation ensures high-quality health and psychosocial care, creating positive health outcomes for patients.

“ACS is committed to advancing high-quality cancer care through capacity building and support for innovative, sustainable models of oncology patient navigation,” said Dr. Arif Kamal, chief patient officer at ACS. “Patient navigation is one of the few interventions in oncology that improves outcomes for the patient, caregiver, and health system, as well as reduces the overall cost of care. It is a crucial component of our commitment to ensuring everyone has a fair and just opportunity to prevent, find, treat, and survive cancer.”



Dr. Arif Kamal

Patient Navigation: A Continuum of Services Built for Patient Experiences

Dr. Kamal noted that patient navigation is not a one-size-fits-all concept. Instead, it's a continuum of services designed to meet individual patient needs – like the continuum of available services people may use to pay their annual income taxes. Some people file with the minimal assistance of an online portal or software program. Others need one-time help from a tax preparation service, while still others need the support of a full-time accountant.

In the case of cancer navigation, services can span the continuum from a peer navigator – someone who has similar lived experiences to the patient and can therefore generate trust – to clinical navigation services provided by a nurse or social worker. These professional navigators can help the patient navigate the logistical challenges of cancer treatment such as how to get to treatment appointments and obtain financial assistance for treatment costs, as well as medical components such as managing symptoms and side effects.

According to Dr. Kamal, ACS thinks about cancer navigation in four ways:

1. **Information navigation.** ACS offers a 24/7 free help line at 800-227-2345 and an online chat line staffed by trained specialists who can connect patients, caregivers, and family members with essential services and resources at every step of their cancer journey. Nearly 50 million people access these resources every year.
2. **Peer navigation.** In June 2023, ACS launched ACS CARES™ (Community Access to Resources, Education, and Support). ACS CARES™ includes a free app that provides personalized information and resources that update as patients age, their situation changes, or new information becomes available. The program also includes 24/7 access to phone support from trained ACS staff, virtual support from trained ACS community volunteers, and in-person support from clinic volunteers. The program works like a dating app, matching patients with volunteers who have similar lived experiences and/or who live in the same area.
3. **Community navigation.** ACS created its Leadership in Oncology Navigation program in response to Cancer Moonshot requests for a program to train and credential non-clinical support staff working as patient navigators in health systems or community health departments. See more information below.
4. **Clinical navigation.** While ACS does not provide direct clinical navigators, it funds existing navigation programs to build evidence for best practices that impact patient outcomes. See more information below.

ACS Cancer Moonshot Highlight #1: Patient Navigation Grant Awards

To address barriers to timely, equitable cancer care across diverse geographies and demographics, in 2022 ACS and partners awarded nearly \$6 million in multi-year grants for patient navigation programs to 20 health systems:

- Boston Medical Center, Boston, Massachusetts
- City of Hope, Los Angeles, California
- Fred Hutchinson Cancer Center, Seattle, Washington
- Harold C. Simmons Comprehensive Cancer Center, UT Southwestern, Dallas, Texas
- Harris Health System, Houston, Texas
- HIMA San Pablo Oncologico-Caguas, Caguas, Puerto Rico
- Huntsman Cancer Institute at the University of Utah, Salt Lake City, Utah
- Markey Cancer Center-University of Kentucky, Lexington, Kentucky
- Montefiore Einstein Cancer Center, Bronx, New York
- Rush University Medical Center, Chicago, Illinois
- Stanford Cancer Institute, Palo Alto, California
- Stephenson Cancer Center, University of Oklahoma, Oklahoma City, Oklahoma
- The University of Chicago Medicine, Chicago, Illinois

- The University of New Mexico Comprehensive Cancer Center, Albuquerque, New Mexico
- University Of Alabama Birmingham, Birmingham, Alabama
- University of Colorado Denver, Aurora, Colorado
- University of North Carolina at Chapel Hill, Chapel Hill, North Carolina
- University of Southern California, Los Angeles, California
- University of Texas Health, San Antonio, Texas
- Virginia Commonwealth University Massey Cancer Center, Richmond, Virginia

Each grant supports an established navigation program for 30 months, with the goal to enhance institutional oncology patient navigation processes, policies and systems and address barriers, gaps and challenges for patients, especially those from populations traditionally excluded. Grantees participate in a bi-monthly learning community to share and hear about the experiences, expertise and lessons of successful patient navigation programs and help improve patient navigation as a practice.

“We are currently at the mid-point of the grant period and are learning that the navigation needs of individual health system populations are unique,” Dr. Kamal said. “The early data generated indicates that additional clarification is needed around how clinical navigation codes can be used and by whom.”

ACS Cancer Moonshot Highlight #2: Oncology Professional Navigator Curricula and Certification Program

In January, ACS, with input from key partners, launched Leadership in Oncology Navigation (ACS LION™), a standardized national curricula and certification program for professional, non-clinical navigators to support people with cancer. The program is designed to align evaluation and adherence to best practices with improved outcomes and professional oncology navigation (PONT) standards, as well as to support new reimbursement for navigation services for Medicare enrollees.

“The ACS and other groups have long promoted the idea of creating a reimbursement mechanism to help overcome barriers associated with starting or scaling community navigation,” Dr. Kamal said. “Historically, these initiatives have been funded through charitable and philanthropic support, meaning they often are short-lived.”

The ACS LION™ program benefits navigators by providing them with:

- Greater credibility with the formal endorsement of their patient navigator expertise.
- Improved knowledge and skills of the complex cancer care system.
- Enhanced understanding of how to tailor support by patient needs.
- Preparation for greater responsibility and professional development.

The program includes a series of asynchronous online learning modules and a proctored exam reflecting the rigor of real-world patient navigation scenarios. In just the first three months since the program’s inception, several hundred people have enrolled.

Dr. Kamal noted that those interested in pursuing ACS LION™ credentialing do not need a background in the medical field. In fact, including those without a health care background will help to create a more diverse patient navigation workforce.

About the American Cancer Society

The American Cancer Society is a leading cancer-fighting organization with a vision to end cancer as we know it, for everyone. For more than 100 years, ACS has been improving the lives of people with cancer and their families as the only organization combating cancer through advocacy, research, and patient support. ACS is committed to ensuring that everyone has an opportunity to prevent, detect, treat, and survive cancer. To learn more about ACS, visit cancer.org or call the ACS 24/7 helpline at 1-800-227-2345. Connect with ACS on [Facebook](#), [X](#), and [Instagram](#).

Reference

1 -Dwyer Cancer Paper: Dwyer AJ, Wender RC, Weltzien ES, Dean MS, Sharpe K, Fleisher L, Burhansstipanov L, Johnson W, Martinez L, Wiatrek DE, Calhoun E, Battaglia TA; National Navigation Roundtable. Collective pursuit for equity in cancer care: The National Navigation Roundtable. Cancer. 2022 Jul 1;128 Suppl 13:2561-2567. doi: 10.1002/cncr.34162. PMID: 35699616.

Unique Partnership Expands Access to Oncology Clinical Trial Patients

As part of their ongoing commitment to The White House Cancer Moonshot, two non-profit organizations have joined forces to improve equitable access to innovative and potentially lifesaving treatments available through oncology clinical trials in the United States.

The HealthWell Foundation announced its sponsorship of Family Reach's Clinical Trial Access Fund last month. The fund provides financial assistance for food, transportation, housing, and utilities to qualified oncology patients. Removing these barriers to care improves the likelihood of ongoing compliance with clinical protocols and a patient's chance of survival.

Meeting Long-Term Patient Needs

Patients enrolled in the program will have the opportunity to access Family Reach's full suite of services designed to help them meet their basic needs over the long term, including navigation connecting them to local programs (food banks, housing assistance, utility payment relief programs, etc.) and tip sheets and guidebooks for saving money and talking about finances during treatment.

"Science has come so far, but it's outpacing the patient experience," said Carla Tardif, Family Reach Chief Executive Officer. "Hundreds of thousands of patients can't afford gas to get to their care center or stable housing. If a patient can't meet these basic needs, cancer treatment is on hold. With the launch of the Clinical Trials Access Fund powered by the HealthWell Foundation, we're breaking down barriers to innovative care and helping more patients gain more moments and memories with loved ones."

According to Eucharia Borden, MSW, LCSW, Family Reach Vice President of Programs and Health Equity, 72 percent of the clinical trial patients served by Family Reach do not have a reliable way to get to treatments, making lack of transportation the biggest unmet need facing clinical trial participants. Just over sixty percent of the clinical trial patients they serve face food insecurity.

"The Clinical Trials Access Fund powered by the HealthWell Foundation will allow us to increase the number of patients we serve," she said.

"Assisting the oncology community in accessing critical medical treatments has always been a priority for HealthWell," added Alan Klein, HealthWell Foundation's Chief Development Officer. "We are thrilled to bring our commitment to clinical trial patients to fruition through our sponsorship of the Clinical Trials Access Fund initiated and managed by Family Reach. We look forward to working together to eliminate obstacles in accessing these trials so oncology patients can focus on compliance and not the financial challenges associated with cancer."



Eucharia Borden

Klein, who devotes a great deal of time to determining where there are gaps in health care, said he would like to see clinical trial sponsors incentivized for exceeding the minimum 12% data threshold for minority population participation in clinical trials. He offered that these incentives could be similar to those encouraging research and development of treatments for rare and infectious diseases. Klein was invited to share his recommendations at the recent [White House Minority Health Forum](#), where he participated in the breakout session: Making Innovation & Research Work for Everyone.

“Increasing minority population participation in clinical trials to make those trials more representative of the general population is in the best interests of the country,” he said. “If the available patient pool is larger, it will be easier to identify and recruit patients. This, in turn, will speed the entire process of treatment discovery and approval.”

Commitments to the Cancer Moonshot

Last September, HealthWell announced its participation in efforts to advance the goals of The White House Cancer Moonshot. At that time, HealthWell committed to:

- Provide more than \$300 million in 2024 to underinsured oncology patients to offset out-of-pocket medication costs, helping them adhere to prescribed treatment regimens and improve their survival. HealthWell is poised to meet this goal through its multiple [funds in oncology](#), including a [Cancer-Related Behavioral Health Fund](#) to assist oncology patients seeking behavioral health services.
- Provide financial assistance to qualified clinical trial patients to address disparities in participation in oncology trials. The partnership with Family Reach’s [Clinical Trial Access Fund](#) accomplishes this goal.
- Support oncology caregivers through a new fund to help individuals with certain out-of-pocket financial needs, seeding \$500,000 for the program. HealthWell plans to launch this new fund later this year.

Family Reach has committed to activities and programs that align with the goals of the Cancer Moonshot as well. Its Community Partnerships program has been recognized by the Cancer Moonshot for its work with regional Black and/or Hispanic/Latino-led non-profits to deliver financial support to patients in their communities. Partnership locations are chosen using state-level data from the CDC and US Census Bureau to identify locations with the highest rates of both cancer mortality and poverty among Black and Hispanic/Latino communities.

“The financial strain of a cancer diagnosis is felt acutely by Black and Hispanic/Latino patients, who experience long-standing racial wealth disparities,” Borden said. “We are working closely with trusted community groups to remove those burdens and create more equitable health care experiences for patients who need them the most.”

Early Detection Program Seeks to Improve Compliance with Recommended Cancer Screenings

As part of our [series](#) on non-profit organizations involved in the White House Cancer Moonshot program, we turn our attention to the [Prevent Cancer Foundation](#). The Foundation is working with the White House and many other partners to advance cancer prevention and early detection across the United States as part of its mission to empower people to stay ahead of cancer through prevention and early detection.

We reached out to the Prevent Cancer Foundation's Senior Communications Manager, Kyra Meister, to learn more about the Foundation's [Early Detection = Better Outcomes](#) campaign.

Cancer Screening Barriers

Real World Health Care: What are some of the biggest barriers people face in terms of getting recommended cancer screenings?

Kyra Meister: According to the Prevent Cancer Foundation's [2024 Early Detection Survey](#), the top reason people reported for being behind on screenings was that they simply didn't know they needed to be screened. This was true across nearly all survey participants.

Fear of a diagnosis or nervousness about the screening examination are other common reasons why people put off getting their routine cancer screenings.

RWHC: How do those barriers become even more burdensome for underserved patient communities, including racial and ethnic minorities and those facing other social determinants of health disparities like food or transportation insecurity?

KM: Our survey showed other barriers faced by different racial and ethnic groups in the U.S. For example, Hispanic adults said inability to afford the cost was a top reason for not being up to date on screenings and Black adults said skepticism of the health care system was a top reason for not being up to date. The list of barriers is long, and can include transportation issues, lack of childcare, difficulty taking time off work, and more.

All of this paints a more detailed picture of how many factors can affect whether someone receives care — and the consequences of these barriers to care are alarming. Across all populations, these barriers make it more difficult to achieve better health outcomes. When cancer is detected early, it can lead to less extensive treatment, more treatment options, and better chances of survival.

Spreading the Word About Cancer Screenings

RWHC: How is the Early Detection = Better Outcomes campaign addressing barriers to cancer screening?

KM: Early Detection = Better Outcomes was launched to educate *all* populations on the routine cancer screenings they need and encourage them to schedule appointments.



Kyra Meister

The campaign shares helpful information that is clear and easy to understand. We educate people on the cancer screenings they need at every age, provide tools to find free and low-cost cancer screenings and share information on how your family health history can impact your cancer risk. We also created an interactive tool that delivers a personalized screening plan in seconds that you can take with you to the doctor's office. We also work with our community partners to overcome logistical barriers, like transportation issues.

It's our goal to meet people where they are — providing them with a toolbox of sorts — so it's easier for everyone to learn what screenings they need to check their health and then to act on that information.

Cancer Screening Milestone Announced

RWHC: Can you update us on how the campaign has been going since it was launched in 2023?

KM: One exciting milestone of our Early Detection = Better Outcomes campaign happened in April, when the White House issued an official presidential proclamation declaring April 2024 as the inaugural National Cancer Prevention and Early Detection Month. The designation of National Cancer Prevention and Early Detection Month was a collaborative effort spearheaded by the Prevent Cancer Foundation and supported by 84 organizations. It was, and will hopefully continue to be in years to come, a critical step toward reducing the impact of cancer on individuals, families, and communities across the U.S.

During the month of April, we saw over 2 billion media impressions and more than 2,000 completions of our cancer screening quiz. We also released a new Public Service Announcement starring Kim and Penn Holderness — winners of the 33rd season of "The Amazing Race" and internet personalities best known for funny, family-centric videos on their social media channels — about scheduling routine cancer screenings.

We've seen so many great conversations across the Foundation's social media channels about people who have been encouraged or reminded to get their routine screenings after viewing our content. We've been so pleased to see these comments about people not only getting screened but coming back with an all clear! It's a great reminder that early detection saves lives and what sharing your story can do for someone who is either hesitant to get screened or has postponed their appointment.

Don't Wait to Get Your Cancer Screening

RWHC: What would you say to someone who may be on the fence about getting screened for cancer?

KM: Don't let your fear keep you from getting checked. If you're going to receive a diagnosis, it is better to get it early. In fact, some screenings are actually preventive, where you can stop cancer before it even starts — like when your provider removes precancerous polyps during a colonoscopy before it ever turns into colorectal cancer.

Also remember that you are not alone. If you have friends or family who are putting off their appointments, offer to go with each other for support, or plan to celebrate with them after you each get your screening. These things can go a long way in motivating yourself and others to check your health.

But the best possible action to take is to talk to your health care provider. Screening guidelines are for those at average risk, so if you have a family history of cancer OR other factors that increase your personal risk, you may need to get screened earlier or more often.

The Link Between Cancer Screening and Cancer Prevention

RWHC: Tell us more about the important role screening plays in preventing cancer.

KM: The five-year survival rate for many cancers is almost 90% when cancer is found in its early stages. Unfortunately, routine screenings are available for only five types of cancer (out of hundreds), which means there are many cancers that go undetected in those early stages. At the Prevent Cancer Foundation, we are investing \$20 million over 15 years for research in innovative technologies to detect cancer early and advance multi-cancer screening. We need to be able to find more cancers in those earlier, more treatable stages. Routine screenings can mean better outcomes for your health — that means more treatment options, more healthy days ahead and more time with the people you love.

As for what we can do right now: Research shows up to 50% of cancer cases and about 50% of cancer deaths are preventable with the knowledge we have today. Knowledge is power — that's why we are dedicated to sharing with others the ways that they can reduce their cancer risk and the routine cancer screenings they CAN and should get right now (even if they have no signs or symptoms).

The Prevent Cancer Foundation is grateful to President Joe Biden, first lady Jill Biden, Vice President Kamala Harris and the entire White House Cancer Moonshot program for recognizing the importance of expanding access to cancer screenings, enabling healthy life habits, stopping more cancers before they start and driving new innovations to create a world where cancer is preventable, detectable, and beatable for all.

Supporting Cancer Patients

RWHC: Does the Prevent Cancer Foundation focus on more than promoting cancer screenings?

KM: We do! Our efforts encompass four pillars: research, education, outreach, and advocacy.

The Foundation funds important research grants and fellowships at some of the most prestigious academic institutions and medical centers across the U.S. The goal of our research program is to identify and fund innovative projects with the potential to make substantial contributions to cancer prevention or early detection.

When it comes to education, we're committed to providing evidence-based information about how you can prevent cancer or detect it early through healthy lifestyle choices, vaccinations, and medical screenings. We get these messages out to adults of screening age through campaigns like Early Detection = Better Outcomes, along with a few others. Our young-onset colorectal cancer campaign, Too Young for This Sh*t, was created to generate discussion around this topic and educate the public about colorectal cancer prevention, early detection and the signs and symptoms of the disease — *even if you think you're too young for this sh*t*. Most people think that colorectal cancer affects only older adults — but today, more adults under 45 are being diagnosed than ever before.

The Foundation reaches out to communities through programs and grants that allow us to fund nationally and globally and act locally. By empowering those who know their communities best, we are able to help implement lifesaving programs that benefit all populations, especially the medically underserved. Since 2007, the Foundation has awarded nearly \$3 million in community grants in 37 states and American Samoa and to the Washoe Tribe.

And lastly, advocacy. By engaging policymakers and grassroots supporters through advocacy, the Foundation promotes the enactment of laws, regulations and funding that prioritize cancer research and prevention and support the needs of cancer patients and their families.

Providing Support to Patients and Families as They Navigate a Cancer Diagnosis

When the White House Cancer Moonshot reignited more than two years ago, the initiative set a bold goal: end cancer as we know it today. It invited the cancer and patient community to devote their energy and ingenuity to efforts that will reduce the death rate from cancer by at least 50 percent over the next 25 years.

The Cancer Moonshot has also called on the cancer community to improve the experience of people and their families living with and surviving cancer. One key to that improved experience is expanding access to services to help patients and their families navigate health care treatments for cancer and other serious illnesses.

"Today, we know cancer as a disease in which we do not do enough to help people and families navigate cancer and its aftermath," noted a White House statement. "We can help people overcome the medical, financial, and emotional burdens that cancer brings by providing support to navigate cancer diagnosis, treatment, and survivorship."

According to The White House, "navigators guide families through every step of their cancer journey. Navigators have been shown to improve health outcomes and the patient experience by reducing time between diagnosis and treatment and increasing treatment completion. These services also lower health care costs by reducing ER visits and hospitalizations and reduce health disparities, including by facilitating access to services to address unmet social determinants of health, such as food and housing insecurity and transportation needs."

"Community Is Stronger Than Cancer"

For 40 years, Cancer Support Community (CSC) has shared the vision that everyone impacted by cancer receives the support they want and need throughout their experience. Underscored by the belief that community is stronger than cancer, CSC strives to uplift and strengthen people impacted by cancer by providing support, fostering compassionate communities, and breaking down barriers to care. Patient navigation is at the heart of many of the services CSC provides as well as the research and policy initiatives it supports.

"We know from our work supporting patients through our Cancer Support Helpline and at our nearly 200 network partner locations that navigation alleviates a number of challenges cancer patients and caregivers face, including, but unfortunately not limited to, barriers to care related to health disparities, financial toxicity, and social and emotional concerns," said CSC CEO Sally Werner, RN, BSN, MSHA. "Additionally, studies have shown that patient navigation is effective



Sally Werner

in improving participation in cancer screening and reducing the time from screening to diagnosis and from diagnosis to treatment initiation. Emerging evidence suggests that patient navigation improves quality of life and patient satisfaction with care in the survivorship phase and reduces hospital readmission in the active treatment and survivorship care phases.¹”

Cancer Support Helpline Provides Free, Personalized Cancer Navigation

One of the many ways in which CSC helps patients and their caregivers navigate their cancer experience is their [Cancer Support Helpline](#) (Helpline,) a free telephone (888-793-9355) and online chat service. CSC’s Helpline is staffed by trained oncology community navigators and resource specialists who can help patients and caregivers get information about cancer and cancer treatment options, identify local support groups, find treatment-related lodging and transportation resources, navigate financial issues, and more.

“Our trained navigators do a lot of legwork to help relieve the burden on patients and their caregivers,” Werner said. “They’re also there to lend an ear and provide emotional support.”

The Helpline proved to be a lifeline for Maria when she needed help navigating finances, medication, and insurance after a blood cancer diagnosis. After surviving treatments, chemo, and a bone marrow transplant, Maria found the cost of medications to treat complications unsustainable for even one month.

Maria recounts how she felt after her first conversation with a CSC Helpline navigator: “I was in a very different place than when I first got on that phone call,” she said. “I had a plan. There were steps. I was optimistic that I and the Helpline navigator would find a solution.”

Maria described her navigator as very hands on, kind, and skillful, with an incredible base of knowledge that was both meaningful and life-affirming.

“She said to me: ‘I’m literally with you. This landscape is familiar to me. Let me show you a couple paths you could take.’ That knowledge combined with the emotional support is exceptional.”

Maria and her navigator worked on grant applications to help her obtain the critical medication. Moreover, because the Helpline’s model of proactive navigation means providing more than just one-time support, Maria and her navigator continued to connect four times over the ensuing eight months.

Digital Mental Health Assessment Connects Patients and Caregivers to Resources

Navigating cancer requires navigating all the emotions, fears, anxiety, and financial stressors that accompany diagnosis, treatment, and survivorship. To help providers rapidly identify patient’s unmet mental health needs and connect them to needed support, CSC offers [MyCareReport](#) (MCR), a digital mental health assessment and referral platform.

The MCR platform and CSC’s distress screeners are deployed across CSC’s and Gilda Club’s [network locations](#). Health care systems, private practices, and oncology centers can license the CSC screeners and digital referral solution without any cost going to the patient or caregiver. MCR includes automated referrals (in-house and community based), and tracks

follow-up care while providing a complete, real-time data source of all screener responses for reporting and analytics.

Notably, MCR has been recognized by CancerX, a public-private partnership and national accelerator created to boost innovation in the fight against cancer as part of the Cancer Moonshot. CSC has been part of the CancerX initiative, whose goal is to reduce the burden of cancer through digital innovation since its founding, including serving on its steering committee.

"Patients with cancer who are diagnosed with anxiety or depression are at an increased risk for emergency department visits and hospitalization and have an almost twofold increased risk of dying by suicide compared with the general population²," Werner said. "MCR helps to bring the patient and caregiver voice and needs to the forefront of care team communication. It enables patients and caregivers to navigate care and treatment, practice self-care, and enhance well-being."

New Mobile App to Provide Precision Support

Another way CSC is harnessing the power of technology to help those impacted by cancer is MyCancerSupport, a no-cost mobile app. The app, currently being tested in six pilot locations, blends CSC's support and navigation services, educational tools and resources, and community connections into one seamless and easy-to-navigate tool. It includes local calendars and event signups, healthy lifestyle information, and in-app messaging to help patients and caregivers engage with CSC and its local resources.

"Unique to this app, compared with the other 400,000-plus health apps in the app stores is the immediate hyper local connection to resources, classes, and support, where and when you need it, Werner said. "We look forward to bringing this essential resource to communities across the country, especially to help historically under resourced and medically underserved patients who don't have easy access to navigation services."

Reference

1. <https://acsjournals.onlinelibrary.wiley.com/doi/10.3322/caac.21788>
2. <https://www.nature.com/articles/s41591-022-01745-y>

HealthWell Foundation Launches Oncology Caregiver Behavioral Health Fund

The HealthWell Foundation has launched an Oncology Caregiver Behavioral Health Fund as part of its commitment to the White House Cancer Moonshot.

Through the fund, HealthWell will provide up to \$2,000 in copayment assistance for prescription drugs, counseling services, psychotherapy, and transportation costs needed to treat or manage behavioral health issues related to providing caregiving to a cancer patient. Eligible grant recipients will have annual household incomes up to 500 percent of the federal poverty level and must be a family member providing care to a cancer patient with an active HealthWell grant.

"As we continue to execute on our initiatives as part of the Cancer Moonshot, we are honored to be able to provide oncology caregivers with the financial support they need to seek and continue behavioral health treatments," said Shela Halper, Chief Foundation Program Officer, HealthWell Foundation. "Recognizing the mental health needs of family caregivers and providing financial assistance so they can access and stay on prescribed treatments is critical, not only for them, but for the loved ones they are caring for. The cost of taking care of their own health and well-being should never be a concern for those who dedicate their lives to caring for others."

"Caring for someone living with cancer is often a 24/7 responsibility. Prioritizing your own health and well-being is challenging and for many caregivers, often an afterthought," said Tia Newcomer, CaringBridge CEO. "Providing access to a range of behavioral health services that are affordable can make a significant difference in a caregiver's life. We commend the HealthWell Foundation for the work being done to provide better support to family caregivers."

To determine eligibility for assistance, visit HealthWell's [Oncology Caregiver Behavioral Health Fund](#) page. Note that all new fund openings and fund re-openings occur at 11:00 a.m. Eastern Daylight Time (8:00 a.m. Pacific) Monday through Friday. To learn more about HealthWell programs and our robust portfolio of disease funds, visit [HealthWellFoundation.org](#).

About CaringBridge

[CaringBridge](#) is a no-cost, 501(c)(3) nonprofit health platform that surrounds family caregivers with support while they care for a loved one on a health journey. A donor-supported nonprofit founded in 1997, the organization offers tools to share and document a health journey, simplify care coordination, and connect caregivers with a supportive community. CaringBridge addresses feelings of overwhelm, isolation, and loneliness by improving emotional health and social connectedness, helping people come together in support of healing. With 320,000 people on the platform every day sending or receiving support, there are over 1,600 messages of love, hope, and compassion posted every hour. And every 12 minutes a new CaringBridge page is started. The CaringBridge community includes all 50 states and more than 242 countries around the world. To learn more, visit: [CaringBridge.org](#).