# Annual Impact Report 2024

Community Is Stronger Than Cancer.



# One Year In: A Message from Our CEO

Sally Werner, RN, BSN, MSHA



Dear Friends,

As I reflect on my first year as CEO of Cancer Support Community, I'm filled with gratitude for your unwavering support. It's my honor to share our collective impact in 2024 and outline our vision for the future. This past year marked my seventh with CSC HQ. Every day, I feel deeply privileged to build upon CSC's remarkable legacy. Together, with our exceptional staff, extraordinary Board of Directors, and dedicated volunteers, we are writing the next chapter in CSC's story.

#### Reflecting on 2024: Progress and Purpose

In 2024, we focused on three key pillars internally: financial stability, strategic growth, and organizational culture. These priorities allowed us to strengthen our organization and deepen our impact.

#### **Expanding to Serve More People**

We expanded our reach through ten new partnerships, including a new location in Ward 8 of Washington, D.C. We also expanded virtual programming, ensuring more people impacted by cancer can find connection and support, no matter where they live.

#### **Advancing Health Equity**

We expanded our Justified Medical Mistrust docuseries, launched the Increasing Dialogue and Engagement through Advocacy Leadership (IDEAL) Ambassador Program, and furthered the work of our Center for Health Equity in Oncology, strengthening our commitment to equitable access to care and resources.

#### **Innovating Programs to Meet Evolving Needs**

We began developing new programs tailored to the shifting landscape of cancer care, including Peer Clinical Trials Support in Spanish and Al-enhanced Open to Options. We also launched pilot programs for key populations, including a virtual support program for people living with multiple myeloma and a novel initiative for people receiving CAR T-cell therapy.

#### **Driving Advocacy for Change**

CSC's Cancer Policy Institute worked collaboratively with policymakers and partners at the federal and state levels to champion policies that make a meaningful difference in the lives of people impacted by cancer.

#### **Leading in Research**

CSC's Research & Training Institute conducted independent and collaborative studies — qualitative, quantitative, and mixed-method — resulting in multiple publications, presentations, and partnerships that are shaping the future of psychosocial oncology by revealing insights about the true impact of cancer on patients and their loved ones.

#### **Elevating Staff Engagement & Culture**

Our team is the heart of CSC. This year, we saw significant growth in staff engagement and satisfaction. Thanks to the dedication of our True North Committee — representing voices from across the organization — we developed and implemented an action plan that has fostered a more inclusive and vibrant workplace culture.

#### **Looking Ahead: Our 2025 Priorities**

As we move into 2025, we remain focused on the second year of our strategic plan, with priorities that reflect our unwavering commitment to those we serve:

#### **Expanding Our Reach: Supporting Patients, Young Adults, and Caregivers**

In 2025, we will further expand our reach to newly diagnosed patients with rare and complex cancers, young adults, and caregivers. We predict 2025 will be the Year of the Caregiver, and we are dedicated to ensuring they are supported as part of our broader mission to serve all those impacted by cancer.

#### **Expanding Health Equity**

We will deepen our outreach to Black/African American and Hispanic/Latino communities, while also extending support to rural, frontier, and underserved urban areas, ensuring equitable access to care and resources.

#### **Innovating Psychosocial Cancer Care**

We will continue to be leaders in psychosocial cancer care, embracing innovation as we continually evolve our signature programs to reflect advancements in screening, treatment, and survivorship. By leveraging technology in new ways, we aim to better engage and support patients, caregivers, and their families.

#### **Shaping CSC's Future Together**

As we look to the future, we are laying the groundwork for the next phase of CSC's growth and innovation. We encourage you to support us as we work to ensure that anyone, anywhere, can access the support they want and need throughout their cancer experience. Because at Cancer Support Community, we know that Community Is Stronger Than Cancer.

Sally Werner, RN, BSN, MSHA

Selly Wenner

CEO, Cancer Support Community



#### **Mission**

Cancer Support Community uplifts and strengthens people impacted by cancer by providing support, fostering compassionate communities, and breaking down barriers to care.

#### **Vision**

Our vision is that everyone impacted by cancer receives the support they want and need throughout their experience.

#### **Our Core Values**



#### **Commitment to Excellence**

CSC is committed to evidenced-based practice and organizational excellence in mission delivery.



#### **No Charge for Services**

CSC endeavors to provide as many programs as possible at no charge to our members/participants.



# **Empowerment through Community**

CSC believes that members/participants can become empowered to improve their health and well-being through opportunities in a community setting in which they gain knowledge, control, and a connection to others.



#### **An Essential Part of Care**

CSC believes that caring for the whole person and family is an essential part of quality cancer care and that all people affected by cancer should be made aware of and have access to psychosocial care as part of cancer treatment and survivorship.



# **Collective Wisdom and Individual Experience**

CSC encourages members/participants to share their own experiences and expertise, building collective wisdom that in turn enriches the community as a whole.



#### **Respect and Inclusion**

CSC is respectful and welcoming to all people touched by cancer with diverse backgrounds and perspectives.

Members/participants are invited to "come as you are" in an environment that welcomes humor, honors learning, and encourages meaningful exchanges with others.

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#### Strategic Priorities

"Cancer Support Community is a light of hope."

Cassie caregiver to her mother

# Improve programs and health equity

so that each person impacted by cancer is engaged, safe, and able to access optimum cancer care, regardless of their race, ethnicity, sexual orientation, gender identity, age, geographic location, ability status, beliefs, and ideologies.

#### **Key Programs and Initiatives**

- Identify and act on barriers to care across the CSC network with continued focus on people from communities of color, Hispanic/Latino, tribal communities as well as people living in rural and frontier communities, and urban healthcare deserts
- Co-develop programs and resources with trusted community and faith-based leaders

#### **Increase reach**

so that we are a community for all those impacted, meeting identified top needs of participants and influencing positive outcomes.

#### **Key Programs and Initiatives**

- Target audience(s) attainment will include newly diagnosed, young adults, and caregivers to help CSC grow geographically and technologically
- Externally-facing deliverables aligned across brand and target audiences (website and programmatic digital tools)

# Provide innovative services

that reflect the changing landscape of cancer care and put us in a competitive and sustainable position of growth.

#### **Key Programs and Initiatives**

- Pave the way with CSC-initiated, signature programs that meet demonstrated patient and caregiver needs
- Leverage our unique organization structure and capabilities (three institutes and our CSC network) and amplify patient/caregiver perspective in advocacy, research, and service delivery





#### **Our Vibrant Communities**

Cancer Support Community (CSC) network partners include local CSCs, Gilda's Clubs, and healthcare partners offering services at 196 locations in the U.S., Canada, and beyond.

In a 2022 study<sup>1</sup>, cancer patients who received network partner distress screening and services had fewer ER visits and days in hospital, while their use of supportive services, including financial counseling increased.

Endnotes are available on page 21

Our network grew from

190 196

locations













# Help Is Just a Call Away with our **Cancer Support Helpline**

In studies done by our Research team in 2024, CSC services were shown to improve quality of life in patients and their loved ones by increasing emotional well-being,<sup>2</sup> feelings of social connection, confidence in problem-focused coping, confidence in managing emotions,<sup>3</sup> cancer-related knowledge, and willingness to talk to their cancer care team<sup>4</sup>

Endnotes are available on page 21

#### Top 5 reported diagnoses

- 1. Breast cancer
- 2. Colorectal cancer
- 3. Lung cancer
- 4. Gynecological cancers
- 5. Prostate Cancer

#### Top 3 reasons for initial call

- 1. Financial stressors (health insurance, medical bills, household expenses)
- 2. Seeking support
- 3. Lodging during treatment

Total Volume 17.971

**Unique Callers** 

4,038

#### On Demand Resources and Support

#### Website

Users 478,199 Pageviews 918,547

Actions\* 3,517,152

#### **MyLifeLine**

CSC's online support community

Active Users 55,409

Pageviews 572,464

Actions\* 1,025,429

#### **Frankly Speaking About Cancer**

CSC's award-winning cancer education series

Booklets/ Copies Distributed

24,158

Video Views

109,047

Social Media Impressions

4,252,055

<sup>\*</sup>Actions taken by visitors includes video streams, downloads, and more

#### Patient Voices

"The navigator was kind, knowledgeable, and calming. Gilda Radner would be proud seeing her name affiliated with this support service."

#### **Helpline Caller**



"That was important for me — coping, getting connected, and having access to these things, especially for my mental health."

#### Courtney

diagnosed with advanced-stage melanoma

GILDA'S CLUB CHICAGO AND CANCER
TRANSITIONS FOR YOUNG ADULTS:
MOVING BEYOND TREATMENT PARTICIPANT.

"Talking to someone like me allowed me to speak freely."

Peer Clinical Trials
Support Program Participant

"Blogging on MyLifeLine is therapy! I find myself more calm after writing a post and the comments and calls that follow are as good as hugs."

# **Karen** *MyLifeLine participant*

#### Increasing our Reach

#### **Prevention in the Park**

CSC launched Prevention in the Park as part of our commitment to reach more people about the importance of cancer screenings. Held in Minor League Baseball and Atlantic League parks, the initiative raises awareness and provides information about screening protocols for different types of cancer, including breast, cervical, colorectal, and lung.

The inaugural events reached 2,500 spectators attending home games with the Kannapolis Cannon Ballers at Atrium Health Ballpark in North Carolina and Lexington Legends at Legends Field in Kentucky.



#### MyCancerSupport App

MyCancerSupport is an easy and accessible way for users to access a wide array of resources and support services. Developed by CSC in partnership with Equiva Health, it combines the exceptional support and navigation services offered by network partners with CSC HQ's award-winning educational tools and resources into a single, easy-to-navigate platform. The app is tailored to each network partner, helping users connect with the programs and services offered by their local Cancer Support Community or Gilda's Club location. Network partner customization and promotion of the app will be ongoing throughout 2025.

878 Downloads

network partners officially launched their apps.

#### Improving Programs, Access & Equity

#### **Patient Perspectives of AI**

See the research presentation

Our work in Artificial Intelligence (AI) explores patients' understanding and perceptions about the use of AI in healthcare and works towards identifying the optimal intersection of AI- and physician-led care while maintaining a patient-centered approach to care. Data collected from our Cancer Experience Registry — an online research study that uncovers the emotional, physical, practical, and financial impacts of cancer — revealed that:

- 98% of respondents have heard of AI, with 31% saying they understand it enough to explain to others and 26% having used AI in the past
- When asked how they feel about the use of AI in healthcare, most people are neutral (48%) with roughly equivalent amounts of people having negative and positive feelings
- 65% agree or strongly agree that they would support the use of AI in healthcare if there is scientific data to show it benefits patients
- 12% agree or strongly agree that they would trust AI to propose the right treatment plan for them

#### Leading Change in Cancer Cachexia Care

CSC is a recognized leader in patient advocacy and education around cancer cachexia, a complex condition that can lead to the unintentional loss of weight and muscle mass. It is often misunderstood and under-diagnosed by healthcare providers. Yet, it can occur in up to 80% of people with advanced cancer.

Our Engagement Tool offers a plain-language definition and phonetic pronunciation of cachexia, illustrations of common symptoms, resources to seek support for the condition, and more.

We found that patients and caregivers who **reviewed the Engagement Tool felt more knowledgeable and willing to talk about cachexia** with their care team.

We presented these findings at the Society for Cachexia and Wasting Disorders annual meeting in December 2024, earning the "Best Clinical Poster" award.



See the research presentation

# Exploring barriers to psychosocial care and sources of resilience for Spanish-Speaking Hispanic and Latino, Rural, and Black People with Cancer

Our landscape analysis study showed that these three medically underserved and historically underresourced communities experience both distinct and similar barriers to psychosocial care and have unique and overlapping sources of resilience.

We learned that:

- Spanish-speaking Hispanic or Latino people with cancer experience unique challenges with accessing culturally competent Spanish-language resources, but find strength in their ability to engage in transnational social networks,
- People with cancer in rural communities want and need more diverse support options that are easily accessible to them where they live and work, but value their humor and tenacity as means of coping with the cancer experience, and
- Black and African American people with cancer strongly desire identity concordance with their providers and recognize the value of prioritizing their own self-care.

Overall, our findings underscore the importance of creating and maintaining customized and community-specific pathways for authentic communication and support among people impacted by cancer. Our research was presented at JADPRO (Journal of the Advanced Practitioner in Oncology) Live 2024 and ACCC (Association of Cancer Care Centers) 41st National Oncology Conference.

See the research presentation



#### Justified Medical Mistrust Films Spark Meaningful Conversations

#### **NEW FILM! Righting the Wrongs**

In this episode of the award-winning short documentary series, we highlight events and personal experiences that contribute to mistrust of the medical community while learning about strategies, programs, and initiatives that individuals and institutions within our healthcare system have developed to earn trust within communities of color, promote the benefits of participating in cancer clinical trials, and achieve inclusive, quality cancer care for all. Our guests from the Black community are patient advocate Rev. Blane J. Newberry, hematologist Dr. Craig Cole, and radiation oncologist Dr. Karen Winkfield.

Watch the Film

#### **How Does a Clinical Trial Benefit ME?**

The film was shown at the Congressional Black Caucus Foundation's 2024 Annual Legislative Conference. The annual event is the leading policy conference on issues impacting African Americans and the global Black community.

Our screening and panelists presented to a standing-room-only only audience of over 100 guests. Our **post-survey** elicited an excellent participation rate of just under 30%.

Watch the Film

This event increased my awareness of the benefits of clinical trial participation in the Black and African-American community.

96%

Strongly agree and agree

N = 27

I have a clearer understanding of how real-life barriers to clinical research are influenced by policy.

88%

Strongly agree and agree

N = 27

I identified at least one policy-based action that I or my organization can take to help increase clinical trial diversity.

85%

Strongly agree and agree

N = 27

#### **Providing Innovative Services**

#### Aiming to Close Gaps in Mental Health Care with AI-Enabled "Precision Support" Digital Therapeutic

One in three cancer patients in hospitals has a mental health condition such as depression or anxiety. CSC partnered with Mika Health to expand access to mental health and other vital support for patients receiving cancer treatments in the US and their caregivers. Mika Health is a global digital therapeutics developer named by Newsweek as one of the World's Best Digital Health Companies in 2024. The Al-enabled evidence-based digital therapeutic, which is certified for its quality and safety as a medical device in the EU, can be customized to specific cancers and treatments to provide a personalized support experience. The tool will incorporate multilingual and multicultural patient and caregiver resources from CSC and insights from our Patient Reported Outcomes (PRO) validated screener and digital assessments.

# Leveraging Technology to Serve Multiple Myeloma Patients

Developed in partnership with Equiva Health, MyMyelomaSupport is a digital platform designed to deliver a wide range of services, resources, and tools to multiple myeloma patients with a focus on reaching medically underserved communities. It features resources from CSC as well as other top multiple myeloma experts. Notably, the platform offers telehealth second opinions with a multiple myeloma specialist. Equiva Health is a health relationship management platform that helps healthcare teams engage patients, streamline care, and improve outcomes.



# Professional Education and Patient Support in Real Time

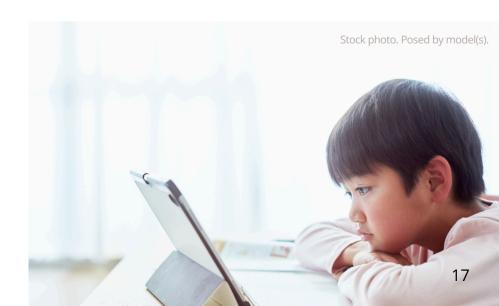
CSC led a breast cancer-specific pilot study of its MyCancerSupport app, combining educational content from Medscape Oncology with CSC content and network partner distribution. Medscape Oncology is the leading online global destination for physicians and healthcare professionals worldwide. Through the pilot, providers were able to access free education (including educational CEUs) and disease and treatment-specific information while providing patient support in real time with the companion app and companion content. Our pilot program included participation from:

#### Addressing Children's Mental Health and Physical Needs

Checking IN is an evidence-informed digital distress screening solution for children with chronic medical conditions that CSC developed with National Institute of Health (NIH)'s National Cancer Institute (NCI) and National Institute of Mental Health (NIMH). It notifies care teams of distress reported by pediatric patients & their caregivers so top concerns can be addressed immediately. In 2024, the first-of-its-kind program screened over 1,500 patients across Levine Children's outpatient clinics in North Carolina.

#### **Top 5 Concerns:**

- 1. Pain
- 2. Sleep
- 3. Tiredness
- 4. Paying Attention
- 5. Appearance



#### Galvanizing Key Communities, Fostering Dialogue, Defining Principles

CSC advocates to improve Utilization Management practices like Prior Authorization and Step Therapy (or "Fail First") so these practices ensure patients get access to high quality care and not just reduce healthcare payers' costs.

On the heels of one of the most consequential elections in recent history, we convened our annual Utilization Management (UM) Summit in Washington D.C. to discuss pressing healthcare issues, foster consensus-focused dialogue, and define principles to help shape the future of UM policy and practice.

Featuring the nation's leading voices on healthcare, 50 patients and caregiver advocates, healthcare providers, policy experts, healthcare innovators, and thought leaders gained valuable insights from:

AiArthritis | Tiffany Westrich-Robertson, CEO

**Arnold & Portner** | Pari Mody, JD, Senior Associate and Monique Nolan, JD, MD, Counsel **Avalere Health** | Sarah Moselle, MPH, Principal

Foundation for Sarcoidosis Research | Tricha Shivas, MBE, Chief of Staff & Strategy

National Association | Grace Grau, DNP, CRNP, ACNP-BC, AACC

of Hispanic Nurses | President-Elect

National Pharmaceutical Council | John O'Brien, PharmD, MPH, President & CEO

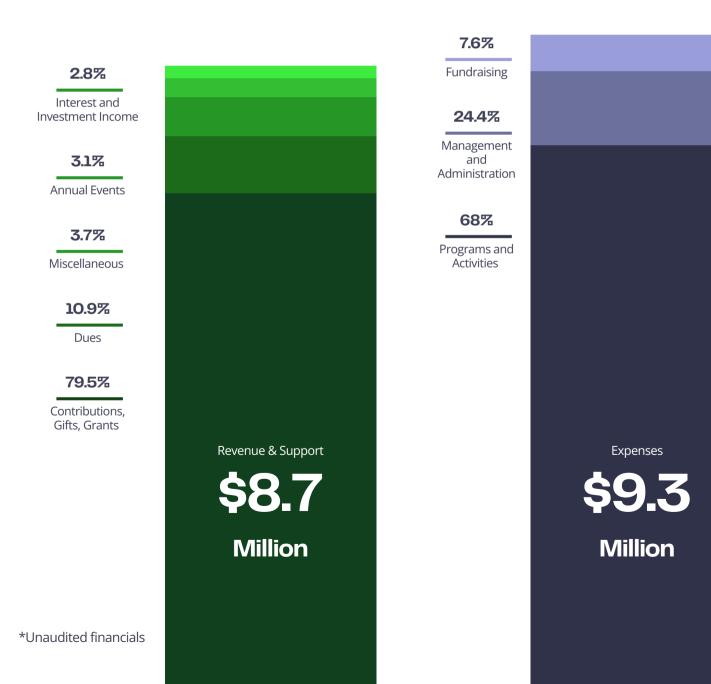
"The Cancer Support Community's Utilization Summit is the Don't Miss Policy Conference of the year. The speakers offer strategic and practical steps that empower patient leaders to catalyze real and meaningful change for all patients and caregivers impacted by chronic disease."

Tricha Shivas, MBE

Chief of Staff and Strategy
Foundation for Sarcoidosis Research

#### **Financials**

The Cancer Support Community remained committed to meeting the growing needs of the cancer community in 2024 while staying true to its mission of providing free support and resources. These mission-driven decisions resulted in expenses of **\$9.3 million** and **\$8.7 million** in revenue as the organization invested in expanding access and deepening impact nationwide.



# With Deepest Gratitude to Our Leadership Donors

We are honored to recognize and thank the generous individuals, foundations, corporations, and industry partners whose gifts of \$5,000 and above have helped us advance our mission. Your partnership makes it possible for us to expand access to critical resources, create meaningful connections, and make a lasting difference for those navigating the challenges of cancer.

AbbVie

Bryan Andes

AstraZeneca

Ray and Fran Baker

Lauren and Aaron Barnes

Barr Charitable Fund

Ann Benjamin

Lauren Benjamin

BeOne Medicines

The Sheri and Les Biller Family Foundation

Walter A. Bloedorn Foundation

**Blueprint Medicines Corporation** 

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Broadway Cares

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Freedom Pay, Inc

Scott Gelber

Genentech

Geron

Gilead Sciences

**GRAIL** 

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Kite

David and Nancy Lesser

Lilly

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Maximus Foundation

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McKinsey & Company, Inc.

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Medscape Oncology

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Lynne and Greg O'Brien

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Pfizer

**PhRMA** 

Dean and Colleen Pisciotta

Sandoz Sanofi

Ken Scalet and Liz Sadove

**Robby Scalet** 

Chuck and Julie Scheper Rodney and Susan Snyder

Sobi

Timothy and Kristina Taggart

Taiho Oncology

Takeda

Holly and Jeffrey Tyson

With heartfelt gratitude, we celebrate a year that again reminded us that **Community Is Stronger Than Cancer**.

Thanks to your unwavering support, we move forward in our mission to uplift and strengthen people impacted by cancer by providing support, fostering compassionate communities, and breaking down barriers to care.

Thanks to your support, Cancer Support Community served more than **617,000** unique individuals by providing over **119,000** services through **3.2 million** visits, calls, and digital connections.

#### **Endnotes**

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