2024 ASH
Annual Meeting

CANCER SUPPORT
COMMUNITY
COMMUNITY IS STRONGER THAN CANCER

Mission

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

Vision

Everyone impacted by cancer receives the support they want and need throughout their experience.

A Recognized Leader in Insight, Advocacy, and Impact

Why Partner With Us

- 196 Global Locations
- 40 years of Psychosocial Oncology Expertise – Professionally Led
- Turnkey Options for Reaching Patients & Caregivers, Research- and Evidence-Based, Data Rich
- Patients, Caregivers, Family Members, Across the Full Spectrum
- Advocacy at the Federal and State level- Patient & Caregiver Voice

Over 1 million people served each year

Almost **300,000** visits to our local CSCs & Gilda's Clubs (network), offered over **58,000** different in-person & virtual programs

Network has grown to **196 currently.**

25,565 calls, emails, & chats with our Helpline Navigators (7,474 outbound calls)

1.8M web pageviews

1 in 8 new MyLifeLine members signed up for Spanish language

82,500 *Frankly Speaking About Cancer* booklets distributed, **61,350** videos viewed

1.6M social media impressions of *Frankly Speaking About Cancer* educational content

Impact Examples

328,887 total visits to local support programs

4.4/5 Helpline callers surveyed responded that “working with my Navigator was valuable”

3,866 Helpline callers received emotional support & support referrals

2,990 Helpline callers received interventions, like lodging & transportation, and help with financial toxicity

> “**The social & emotional support** of regular conversations with an extremely thoughtful, competent, caring, empathic social worker **was valuable beyond words.**
>
> Car T Cell Patient

Cancer Transitions CAR T Program:

- **100%** felt more connected to other survivors
- **100%** of caregivers said their participation will benefit the survivor they care for
- **100%** are more hopeful about their future
- **83%** feel more confident they can talk to the healthcare team regarding their loved one’s post-treatment care

Peer Clinical Trial Support Program:

97% of Peer Clinical Trial Support program participants left with positive perceptions of clinical trials (before only 65% felt +), **85%** reported they were likely to participate in a clinical trial

Overall clinical trial knowledge increased from **43% to 98%** after participating

39% more participants talked to their HCP about clinical trials after participating

Signature Programs

Patients, Caregivers, Survivors

Research and data driven

MIXED METHODS

QUALITATIVE RESEARCH

SURVEY RESEARCH

CREATING NEW MEASURES OF THE CANCER EXPERIENCE

HEOR AND REAL-WORLD EVIDENCE

Center for Health Equity in Oncology

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Amplifying Reach via Network Partners

Direct Service

- + HELPLINE AND MYLIFELINE
- + DISTRESS SCREENERS
- + 196 GLOBAL NETWORK PARTNERS

Education & Awareness

- + FRANKLY SPEAKING SERIES

Policy & Advocacy

- + FEDERAL
- + STATE

2025
Strategic Priorities

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Meeting Patients, Caregivers, & Survivors Where They Are

Research

- **AI in Healthcare – Patient perceptions**
- **Investigating barriers to accessing CAR-T in community setting**
- **Engaging patients to better understand their experience with bispecific antibodies**
- **Assessing the prevalence of social toxicity in specific cancer types and its impact on patient-reported outcomes**

Expanding Impact

- **Open to Options: AI**
  - Cancer type-specific AI training (starting in MM)
- **Customized proactive navigation**
  - Bispecific Navigation
  - CAR T Navigation
  - Clinical Trial Navigation
- **Community Health Worker**
- **Cancer Transitions**
  - CAR T

Programs and Health Equity Initiatives

- **Rural and Frontier Support**
- **Clinical Trial Initiatives**
  - Peer Clinical Trial
  - O2O AI Shared Decision Making
  - Justified Medical Mistrust
  - Clinical Trial Navigation
- **Bridging the Digital Divide: MyMyeloma**
- **Native American Community Engagement**
  - Access Summit

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2025 CAR T Priorities

CAR T In The Community

- **Investigating barriers to accessing CAR-T in community setting**

Objectives

1. **Gain Insights into Barriers to Accessing CAR T Treatment at Community Centers:** Collect and analyze qualitative data from patients, caregivers, and subject matter experts to explore the difficulties faced in accessing CAR T therapy, with a particular focus on underserved populations and community cancer centers.
2. **. Identify Policy Solutions to Address Access Barriers:** Collaborate with health care providers and health policy advocates to use the insights gathered to inform policy recommendations that can address systemic and logistical barriers, enhancing access to CAR T therapy

CAR T Concierge Navigation

- Proactive patient navigation provided by a masters-prepared Licensed Clinical Oncology Social Worker.
- CAR T Navigator engages with patients and their caregivers, empowering them and their families to manage the social, emotional, practical, and financial barriers to care.
- CAR T-cell proactive navigation includes initial and follow up distress screening, support, education and resource navigation for transportation, lodging, financial assistance, and other practical needs as appropriate.

Cancer Transitions CAR T

- Pilot Phase Report
- A culturally relevant and medically accurate psychosocial education and support program designed to meet the needs of caregivers and survivors who have undergone CAR T cell therapy as they transition into post-treatment survivorshi
- Consists of Four Sessions
  1. Get Back to Wellness/ Refocusing on You
  2. Emotions and Coping.
  3. Relationships and Community
  4. Medical and Practical Matters

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2025 Bispecifics Programming

Research

- **Understanding Patient and Caregiver Experiences with BsAbs in Community Settings**

Objectives

- Identify gaps in patient and caregiver education and support
- Explore the differing educational and support needs between patients, caregivers, and healthcare providers
- Investigate logistical and financial challenges, particularly issues around insurance coverage, faced by patients during treatment
- Determine the prevalence and severity of side effects

Educational Resources

Development of Comprehensive Frankly Speaking About Cancer Materials

- Support patients and caregivers' understanding of the treatment process and timeline.
- Guidance on managing and discussing side effects with their healthcare team.
- Strategies for explaining the treatment process to friends and family.
- Tips for coping with the treatment experience and related side effects.

BsAbs Navigation

- Proactive patient navigation provided by a masters-prepared Licensed Clinical Oncology Social Worker.
- Logistical and Financial Needs
- Challenges related to traveling for treatment.
- Financial navigation needs during the treatment process.
- Issues with insurance coverage with transferring to academic center
- Needs when patients are at their primary oncologist versus the "step-up dosing center."

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2025 Policy Priorities

- **Inflation Reduction Act**
  - Medicare Drug Price Negotiation Program (MDPNP)
  - Medicare Prescription Payment Plan (M3P)
  - *ORPHAN Cures Act* (H.R. 5539/S. 3131) & *EPIC Act* (H.R. 7174)

- **Utilization Management (UM)**
  - Step therapy & the *Safe Step Act* (H.R. 2630/S. 652)
  - Copay Accumulators/Maximizers & the *Help Ensure Lower Patient (HELP) Copays Act* (H.R. 830/S. 1375)
  - Alternative Funding Programs (AFPs)
  - Prior authorization
  - Use of Artificial Intelligence (AI) in UM practices

- **CAR-T in the community**

- **340B resources and toolkits**

- **Cancer prevention & early detection access and coverage**
  - Biomarker testing
  - *Medicare Multi-Cancer Early Detection (MCED) Screening Coverage Act* (H.R. 2407/S. 2085)
  - *Reducing Hereditary Cancer Act* (H.R. 1526/S. 765)
  - *PSA Screening for HIM Act* (H.R. 1826)

- **Patient Navigation**
  - CEO Patient Navigation Forum

- **Increase clinical trial diversity & break down barriers to participation**
  - *Clinical Trial Modernization Act* (H.R. 8412)

- **Patient engagement & patient value assessments**

- **Protecting the Six Protected Classes**

- **Telehealth access & coverage**
  - *Telehealth Modernization Act of 2024* (H.R. 7623/S. 3967)

- **Oral Parity & the *Cancer Drug Parity Act* (S. 2039)**

- **Drug shortages**

- **Prohibiting discriminatory measures in determining coverage and cost of care under federal programs**
  - *Protecting Healthcare for All Patients Act* (H.R. 485)

- **Reauthorization of ACA tax credits**

Compassion. Community.
Knowledge. Research. Advocacy.

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