Shooting for the Moon

THE CANCER SUPPORT COMMUNITY ACCELERATES INNOVATION

2016 ANNUAL REPORT







ABOUT THE CANCER SUPPORT COMMUNITY

As the largest professionally led nonprofit network of cancer support worldwide, the Cancer Support Community[®] (CSC) is dedicated to ensuring that all people impacted by cancer are empowered by knowledge, strengthened by action, and sustained by community. CSC achieves its mission through three areas: direct service delivery, research, and policy. The organization includes an international network of Affiliates that offer the highest quality social and emotional support for people impacted by cancer, as well as a community of support available online and over the phone. The Research and Training Institute conducts cutting-edge psychosocial, behavioral, and survivorship research. CSC furthers its focus on policy through its **Cancer Policy Institute**, informing public policy in Washington, D.C. and across the nation. For more information, please call 1-888-793-9355, or visit CancerSupportCommunity.org.

So that no one faces cancer alone[®]



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Dear Friends of the Cancer Support Community,

Thank you for allowing us to be a part of your journey, for your continued support, and, most of all, for your dedication to accelerating innovation in cancer care. With your help, we can shoot for the moon!

2016 was a landmark year for the Cancer Support Community—a year in which our organization saw tremendous growth, embarking on new and important alliances, and expanding programs and services designed to educate and empower patients and their families. One of our most significant achievements was joining the Cancer Moonshot initiative: a national call from Vice President Joe Biden to accelerate research and advance efforts to prevent, diagnose, and treat cancer. At the National Cancer Moonshot Summit in June 2016, CSC had the privilege to speak to a large and diverse audience of health care providers, researchers, and policymakers about a core belief that drives all of our activities every day—that the patient is our "True North," the focal point of everything we do.

At the Cancer Support Community, we believe in the power of patient-directed care. We encourage cancer patients to advocate for themselves so that everyone can receive high-quality, comprehensive care. We must create solutions for the issues facing cancer patients, such as understanding the patient and caregiver experiences, and providing extensive educational and support resources. There must be transparency between patients and their health care teams. We work to achieve this by sharing insight with the broader health care community about the complete cancer experience. This also means learning more about the physical, emotional, social, and financial impact of cancer on patients and their caregivers.

Last year, the Research and Training Institute utilized findings from the Cancer Experience Registry to accelerate cancer care research. These findings included information about the patient and caregiver experience—in particular, the effects of cancer on their emotional and psychosocial health—from patients and caregivers themselves. We continue to work toward bridging the gap between research and practice by using the insight from our community to improve our programs and to raise awareness of emotional and social issues within the broader cancer community. The Cancer Policy Institute worked directly with policymakers and advocates to create a transparent system, so that all patients have access to high-quality, comprehensive cancer care. This year the Cancer Policy Institute launched a comprehensive study, *Access to Care in Cancer 2016: Barriers and Challenges*, to better understand patients access to cancer care.

In 2016, we moved closer to ensuring that no one faces cancer alone. Our Affiliate Network, Cancer Support Helpline, distress screening tools, and *Frankly Speaking About Cancer®* resources all connect cancer patients with information and people. By creating patient communities in person, online, and over the phone, we give patients the opportunity to drive their cancer care. With our belief that patients are the most important guide to what we do, we will continue to innovate and improve the cancer experience. With your continued support, we will reach the moon.

Thank you and warmest regards,

K. Thildhof

KIM THIBOLDEAUX Chief Executive Officer



Jul H. DUNOVSIK

JILL DUROVSIK Board Chair



CSC WAS FEATURED IN:

What Will 2017 Bring for Joe Biden's Cancer 'Moonshot'?

----USA Today

How to Cope With a Difficult Diagnosis

-Real Simple

Tips and Resources for Coping With Cancer Treatment Costs

-CureToday.com

Cancer Patients Say they Face High Costs, Risks When Care Delayed

----USA Today

Medicaid Cancer Patients Receive Subpar Care

-Modern Healthcare

FRANKLY SPEAKING ABOUT CANCER



1,9/3 WORKSHOP PARTICIPANTS



248,295 WEBPAGE VIEWS



53,675 MATERIALS DISTRIBUTED



7,186 WEBINAR VIEWS





27,688,316



ENGAGEMENTS

E 3



374,087



PARTICIPANTS



WITH METASTATIC LUNG CANCER





CANCER STOMACH (GASTRIC AND GASTRO-ESOPHAGEAL) CANCER



Research

When you contribute data, when you identify those issues, it's a way of making your voice heard and it's a way of joining your voice to a broader community. In today's world, as much as the testimonial is important, as much as the individual story is important, there is a compelling need to have a community of voices, a unified story that is presented to the people who make decisions about where funding is going to come from, what policy is going to be, what kind of care is going to be available, and who is going to pay for that care.

-Cancer Experience Registry Participant

Bridging the Gap Between Research and Practice

CSC's **Research and Training Institute (RTI)** is the first Institute completely dedicated to understanding the cancer patient and caregiver experience. The Institute seeks to examine the critical role of social, emotional, and behavioral needs of patients and the ways in which interventions can improve the lives of people facing cancer. Our ultimate goal is to ensure that patient and caregiver voices are heard. We combine scientific rigor and evidence-based research together with innovative approaches to collecting, evaluating, and disseminating our findings on patient survey data. We bridge the gap between research and practice by using the information and insights from our patient and caregiver communities to improve our programs and raise awareness of the emotional and social aspects of the cancer experience with health care providers and policymakers.

Over the past year, we have expanded the **Cancer Experience Registry**—with more cancer-specific Specialty Registries and more registrants—putting more tools in place to greatly accelerate the overall CSC vision. We have gained a better and broader understanding of patient values as they relate to treatment decision-making, and we've validated CancerSupportSource[®], an innovative distress screening tool for caregivers.

Connecting with the Cancer Community

The **Cancer Experience Registry** is a unique online community of over 12,000 cancer patients and caregivers. It provides a place for people impacted by cancer to connect with one another, to assure that their voices are heard, and to communicate their experiences to the broader cancer community. The Research and Training Institute gathers information from the Registry so important and real-world patient and caregiver perspectives can make a difference in cancer treatment and care.

We are committed to increasing the number of Cancer Experience Registry participants in 2017. But numbers alone are not enough: we are also working to gain a deeper understanding of the issues that affect people with specific cancers. For that reason, we now have 10 Specialty Registries to help us document these different cancer experiences.

New Initiatives on Patient Value and Caregiving

Over the past year, the Research and Training Institute conducted groundbreaking research to learn more about and explain how cancer patients defined value in health care. Initially, the team co-chaired a working group with the American Society of Clinical Oncology to better understand the patient definition of value. From these discussions, the Research and Training Institute then developed a survey to quantify what patients value: what really matters to them and what brings them hope in the face of their challenges with treatment and illness.

In addition, experts have long recognized that caregivers are an essential component of the health care system, and that caring for someone diagnosed with cancer is often accompanied by emotional distress and health consequences. That's why there is a tremendous need to provide appropriate, effective, and timely supportive care services to caregivers. In 2016, the Research and Training Institute team conducted a study to validate the need for a web-based distress screening tool for family members and loved ones caring for someone living with cancer. This represented a first step in building CancerSupportSource for Caregivers—bringing cancer distress screening, referral, and follow-up to the entire family.

Shaping the Future through Research

At the Research and Training Institute, we understand that harnessing and communicating the patient voice can only be achieved through community-initiated research collaborations. Yet improving the cancer experience and outcomes for patients and caregivers demands that CSC takes an active leadership role in communicating what is learned to the broader cancer community, and use this knowledge, wisdom, and insight to affect real change.

The Research and Training Institute would like to thank the following organizations for their support in 2016: AbbVie, Amgen Oncology, Bristol-Myers Squibb, Genentech, Gilead Sciences, Novartis, and Takeda Oncology.

SPECIALTY REGISTRIES

- Breast Cancer
- Caregivers
- Chronic Lymphocytic Leukemia
- Chronic Myeloid Leukemia
- Lung Cancer
- Melanoma
- Metastatic Breast Cancer
- Multiple Myeloma
- Prostate Cancer
- Stomach (Gastric and Gastro-esophageal) Cancer

In 2016, Cancer Experience Registry[®] participants voiced their opinions about many important topics, including financial toxicity (stress related to high cost of living with cancer), clinical trial participation, and doctor-patient communication. These findings have informed policy efforts and the development of our newest **Frankly Speaking About Cancer** educational program (which encompasses workshops, webinars, and materials) focused specifically on clinical trials.

Sharing the Patient Voice

Sharing what we learn with the cancer community is vital to ensuring that the patient voice contributes significantly to any activities and initiatives that are designed to accelerate innovation in cancer care. In 2016, RTI members presented important research and findings at leading cancer and public health symposia, including the American Society for Clinical Oncology (ASCO) Annual Meeting, ASCO's Survivorship Symposium, the American Society for Hematology Annual Meeting, the National Comprehensive Cancer Network, San Antonio Breast Cancer Symposium, Society for Behavioral Medicine Annual Meeting, Association for Value Based Cancer Care Annual Meeting, Biennial Cancer Survivorship Research Conference, and the American Psychosocial Oncology Society Annual Meeting.

These presentations, poster sessions, symposia, and published peer-reviewed articles addressed the critical issues patients and caregivers face. The team elevated findings on distress screening as an important component of communication between doctors and patients and the impact of financial toxicity on emotional health. They also highlighted patient attitudes and beliefs that influence treatment adherence, the impact of symptom burden on patient communication, and the ways in which perceptions of the cancer experience have changed over time.

Policy

IOT

Elevating Patient Voices

Throughout 2016, CSC's **Cancer Policy Institute** brought unique and meaningful insight to policy discussions about the comprehensive patient experience and evidence-based solutions that improve patient outcomes and decrease overall cost. Focusing on the core tenets of access to care for all patients, with quality as a central theme and research as a critical priority, the Institute is proud to be advancing an ambitious agenda—on Capitol Hill, with the regulatory community, and in conjunction with professional standard-setting organizations. The Cancer Policy Institute ensures that all people affected by cancer have access to the highest-quality, patient-centered care available.

R MOONSHOT

Striving to Achieve the Cancer Moonshot

Immediately following the announcement of Vice President Biden's Cancer Moonshot initiative in January of 2016, the Cancer Policy Institute was fully engaged. In addition to frequent communication and meetings with the Cancer Moonshot staff at the White House, we freely offered CSC resources to the cause, including materials from the **Frankly Speaking About Cancer Clinical Trials** program, findings from our Cancer Experience Registry, access to the Understanding Access to Care in Cancer study, and learnings from our Affiliate Network.

On June 29, 2016, Cancer Support Community CEO Kim Thiboldeaux joined Vice President Biden and many other leaders from the cancer community at the National Cancer Moonshot Summit. Kim spoke about the importance of the patient perspective in working to achieve the Cancer Moonshot objectives of making ten years of progress in cancer prevention, diagnosis, and treatment in just five years. Additionally, CSC hosted thirty regional Cancer Moonshot Summits across the Affiliate Network, bringing the Cancer Moonshot to diverse communities all over the United States. For more information about the Institute's involvement in the Cancer Moonshot initiative visit: cancersupportcommunity.org/partnering-cancer-moonshot-initiative.

THANKS TO THE CANCER SUPPORT COMMUNITY AFFILIATES WHO HOSTED CANCER MOONSHOT SUMMITS IN THEIR COMMUNITIES:

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CANCER MOONSHOT

MOONSHO

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- CSC Santa Monica
- CSC Delaware
- CSC Greater Miami
- UF Health Cancer Center-Orlando Health
- Gilda's Club South Florida
- CSC Atlanta
- OSF Saint Francis Medical Center
- CSC Central Indiana
- Gilda's Club Evansville
- Gilda's Club Quad Cities
- Gilda's Club Metro Detroit
- CSC Greater Ann Arbor
- Gilda's Club Twin Cities
- CSC Greater St. Louis
- · Gilda's Club Kansas City
- CSC Montana
- CSC Central New Jersey
- CSC Greater Cincinnati-Northern Kentucky
- CSC Central Ohio
- CSC Greater Lehigh Valley
- CSC Greater Philadelphia
- Greenville Health System
- Gilda's Club Nashville
- Whitman-Walker Health Clinic
- Gilda's Club Madison



CANCER SUPPORT COMMUNITY Achel Neuer of Education and Hepe

Ensuring that all people impacted by cancer are empowered by knowledge, strengthened by action, and sustained by community.

Exploring Access to Care in Cancer

The Cancer Policy Institute, with critical research-gathering and data analysis support from the Research and Training Institute, launched a comprehensive study in 2016 to better understand patients access to cancer care—and the barriers that can impede their access. As a part of the survey, patients were asked about both their broad and specific experiences with health care. Issues explored include:

- Access to and coverage of health
 insurance
 - Cost of care
- Access to services
- Impact of cost containment measures such as prior authorization, step therapy, and clinical pathways
- Treatment decision-making and communication with the health care team
- Results from the project were compiled into a published report and shared with patients, advocates, providers, policymakers, and other stakeholders in November at the Access to Care in Cancer 2016 event. The full report was also distributed to every Congressional representative on Capitol Hill.

The report garnered over 14 million media hits and impressions, and CSC was proud to be the vehicle to help communicate the patient perspective on such an important issue. Key findings are on the next page.

The Access to Care Survey was made possible thanks to grants from: Amgen Oncology, Bristol-Myers Squibb, Celgene Corporation, Genentech, and Novartis.

Delivering the Cancer Insurance Checklist

The Cancer Policy Institute team led a coalition of 19 advocacy partners to deliver the Cancer Insurance Checklist in English and Spanish to cancer patients. Both lists are distributed across the broader cancer community as a tool to help patients make informed decisions about their health care and to allow them to shop for coverage on the state insurance exchanges. Following a content update in 2016, 10,000 copies were distributed through the CSC Affiliate Network and online properties, and excerpts were delivered via **CSC's Frankly Speaking About Cancer** radio show and through multiple, strategic social media placements. Since its launch, more than 100,000 individuals have benefitted from the Cancer Insurance Checklist.

The Cancer Insurance Checklist is made possible thanks to a grant from Novartis.

Defining Patient Values

The Cancer Policy Institute partnered with the Research and Training Institute to define value in cancer care through the voices of people living with cancer. The outcomes of the analysis of 1,415 patients were disseminated in abstracts presented at the ASCO Annual Meeting, and delivered at the Association for Value-Based Cancer Care meeting in 2016.

The Cancer Policy Institute continues to incorporate findings from the Research and Training Institute to inform its public comments in response to proposed value frameworks, payment models, and proposed system changes that will affect individuals impacted by cancer. In 2016, the Cancer Policy Institute submitted comments on many of these issues including:

- Institute for Clinical and Economic Review (ICER) Multiple Myeloma Evidence Report
- Institute for Clinical and Economic Review (ICER) Lung
 Cancer Evidence Report
- Institute for Clinical and Economic Review (ICER) Value Assessment Framework
- Medicare Part B Proposed Rule
- The Medicare Access and CHIP Reauthorization Act (MACRA)

Additionally, the Cancer Policy Institute team has worked with the American Society of Clinical Oncology, the National Comprehensive Cancer Network, the Association of Community Cancer Centers, the Community Oncology Alliance, the National Health Council, FasterCures, and other organizations to further expand their scope and define their work on patient value in cancer care.

Program work on defining patient values is made possible thanks to grants from: Amgen Oncology, Bristol-Myers Squibb, Celgene Corporation, and Genentech.

Key Findings

This report contains numerous findings regarding patient access to care in cancer.

Key findings include:

TOPIC AREA	FINDINGS
Access to Health Insurance	AFFORDABILITY AND MEDICAID NELIGIBILITY WERE CITED AS REASONS FOR ACK OF COVERAGE
Access to Services	A QUARTER OF RESPONDENTS DID NOT DID N
Treatment Decision– Making	37.6% OF RESPONDENTS R E P O R T E D WANTING MORE IN CARE AND T E A T M E NT D E C I S I O NS PEO PLE WITH COVERAGE THROUGH MEDICALD OR THE MARKET PLACE MORE FREQUENTLY R E P O R T E D NOT HAVING WITH PROVIDERS DESCRIPTION MARKET PLACE MORE FREQUENTLY R E P O R T E D NOT HAVING WITH PROVIDERS DESCRIPTION MARKET PLACE MAD NEVER HEARD OF CLINICAL PRACTICE GUIDELINES DESCRIPTION MARKET PLACE MAD NEVER HEARD OF CLINICAL PRACTICE MITH PROVIDERS DESCRIPTION MARKET PLACE MAD NEVER HEARD OF CLINICAL PRACTICE MAD NEVER MAD NEVER HEARD OF CLINICAL PRACTICE MAD NEVER MAD NEVER MA
Cost of Care	42.6% OF RESPONDENTS REPORTED THAT THEIR OUT-OF- POCKET COSTS HAVE BEEN LARGER THAN EXPECTED
Cost Containment Strategies	MORE THAN 45% of RESPONDENTS WERE REQUIRED TO GET PRIOR AUTHORIZATION FOR A TREATMENT THAT WAS PRESCRIBED TO TREAT THEIR CANCER MORE THAN 14% of RESPONDENTS DESPON

THE CANCER POLICY INSTITUTE IS PROUD TO COLLABORATE WITH THE FOLLOWING PARTNERS ON KEY INITIATIVES:

- Alliance for a Stronger FDAAmerican College of Surgeons
- Commission on Cancer
- Alliance for Quality Psychosocial Care
 Cancer Leadership Council
- Coverage Counts
- Immuno-Oncology Valuation Policy Advisory Group
 Innovation Working Group
- Institute for Clinical Immuno-
- Oncology Advisory Board National Health Council
- Partnership to Improve Patient Care
 Patients Equal Access Coalition
 Patient Quality of Life Coalition

One Voice Against CancerPartnership for Part D Access

- Regulatory Education and Action for Patients
- State Patients Equal Access Coalition

Advancing Distress Screening

A key priority for CSC is the seamless integration of patient experience metrics and appropriate follow-up care across the cancer experience. Screening for cancer-related emotional distress can illuminate specific causes of distress so they are addressed quickly before becoming a barrier to treatment and care. Throughout 2016, the Cancer Policy Institute engaged in extensive discussions about the benefits of distress screening across a number of stakeholder groups, including:

- Capitol Hill
- Food and Drug Administration
- National Cancer Institute
- Centers for Medicare and Medicaid Innovation

CANCER POLICY INSTITUTE ADVISORY BOARD

The Cancer Policy Institute benefits from an expert and active advisory board that provides substantial advice and guidance on cancer advocacy strategies. Thank you to Cancer Policy Institute Advisory Board members:

- Jeff Allen, PhD
- Lauren G. Barnes, MHS
- Jeff Belkora, PhD
- Linda J. Blumberg, PhD
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- Dylan H. Roby, PhD
- Lisa Simpson, MB, BCh, MPH, FAAP
- MPH, FAAP
 Daniel E. Smith, JD

Leading Policy Roundtable Discussions

Throughout the year, the Cancer Policy Institute brought together a wide array of representatives from patient advocacy groups and policy organizations for roundtable discussions to explore topics relevant to cancer care and other life-threatening illnesses. In 2016, the Cancer Policy Institute hosted roundtable discussions on topics that included:

- Comprehensive care models inclusive of the Commission on Cancer Patient Centered Standards
- The implementation of 340B designation and the impact on patient care
- The impact of off-label communications on patient care
- Elements of quality care through the Alliance for Quality Psychosocial Care
- Access to health insurance through the Cancer Insurance Checklist coalition
- Further development of patient centered drug development through the Prescription Drug User Fee Act



Hearing from the **Grassroots** Advocacy Network

Established to capture and represent the patient voice from all corners of the United States, **CSC's Grassroots Advocacy Network** has grown to more than 3,000 patients and other supporters. This activated network participates in training, responds to calls to contact elected officials on behalf of patients with cancer, and shares its voice through research. Through the Grassroots Advocacy Network, participants have the ability to:

- Engage in a webinar training series on topics that include Medicare Part B and clinical trials advocacy
- Join regional advocacy training with members from eight CSC Affiliates
- Attend Affiliate advocacy training with Affiliate leaders from around the U.S.
- Conduct multiple member meetings at both the federal and state levels

Activities of the Grassroots Advocacy Network are made possible thanks to grants from Bristol-Myers Squibb and Celgene Corporation.

THANK YOU TO CANCER POLICY INSTITUTE'S 2016 SPONSORS

PLATINUM: Avalere Health Bristol-Myers Squibb Takeda Oncology

GOLD: Amgen Oncology Lilly Oncology Merck & Co. Novartis Pfizer Oncology SILVER: Astellas & Medivation Boehringer Ingelheim

Celgene Corporation Eisai, Inc Genentech GlaxoSmithKline Incyte Corporation Janssen Oncology Taiho Oncology

Carol Burnett

Education

Creating New Immunotherapy Education

Patients and caregivers are increasingly requesting trusted information on immunotherapy, as these new treatment types receive greater attention among the health care community and the general public. With input from patients and caregivers who have received immunotherapy, the following resources were created or updated in 2016:

- Frankly Speaking About Cancer: Your Immune System online resources now feature stories and videos of patients and caregivers who participated in CSC's Immunotherapy Patient and Caregiver Summit
- Frankly Speaking About Cancer: Your Immune System fact sheet series now incorporates stories and insights from patients and caregivers
- Frankly Speaking About Cancer: CAR T Cell Immunotherapy, a new fact sheet
- Three new Frankly Speaking About Cancer: Your Immune System & Cancer Treatment webinars
- Live workshops with more than 380 participants at local Cancer Support Community and Gilda's Club locations

For more information about immunotherapy, visit www.CancerSupportCommunity.org/Immunotherapy.

The Cancer Support Community thanks AstraZeneca, Bristol-Myers Squibb, Juno Therapeutics, and Merck & Co. for helping to make our new immunotherapy programs and materials possible.

Expanding Frankly Speaking About Cancer

In 2016, CSC's landmark educational program, *Frankly Speaking About Cancer*, expanded to incorporate more of the unique educational needs of patients and families. This expansion included the following new and updated publications:

- CSC's Frankly Speaking About Cancer: Lung Cancer book, updated and made available as an eBook with patient experience videos
- Lung Cancer: What You Need to Know, published in both English and Spanish
- Treatments for Advanced and Metastatic Lung Cancer, which includes a tearout discussion tool to help improve patients' communication with their health care teams



- Frankly Speaking About Cancer: Acute Lymphocytic Leukemia, now available as both an eBook and a downloadable PDF
- 10 Tips for Living Well With Myeloproliferative Neoplasms (MPNs)
- Frankly Speaking About Cancer. Putting the Focus on Stage III Melanoma, created for patients and caregivers living with high-risk melanoma



• Frankly Speaking About Cancer: Caregivers booklet, redesigned to make it easier to download and read

Thanks to Amgen Oncology, Bristol-Meyers Squibb, Celgene Corporation, Incyte Corporation, and Lilly Oncology for making these additional publications possible.

Meeting the Need for Additional Immunotherapy Information

In November 2016, patients and caregivers from across the United States gathered for the Cancer Support Community's Immunotherapy Patient and Caregiver Summit. Throughout this two-day learning event, attendees participated in a series of lectures and breakout discussions to share common experiences, expand their knowledge of immunotherapy, explore opportunities for self-advocacy, tell their stories, and help identify gaps in existing immunotherapy patient-education materials. What an amazing, informative, and empowering two days it has been. Thank you all for the hard work, time, and effort put into this summit... I'm so appreciative of CSC for continually extending these opportunities for help and showing that we are not alone. Thank you.

—Frances

Empowering Listeners with our Radio Show

Frankly Speaking About Cancer includes an internet radio show and podcast that empower and encourage listeners to live well with cancer. Hosted by Cancer Support Community CEO Kim Thiboldeaux, the show invites patients, caregivers, health care professionals, and policy experts to share their cancer experience, including personal stories of hope. Throughout 2016, more than 6,800 people tuned in each month. New



episodes air on Tuesday afternoons and are available for streaming and download from iTunes and the Apple Podcasts app. Episodes are archived at <u>CancerSupportCommunity.org/RadioShow.</u> 2016 episodes included:

- A Prostate Cancer Conversation with Ken Griffey, Sr.
- Paying for 'Real Life' When You Have Cancer
- Cancer Survivor's Guilt

- Broadway's Golden Couple: Marin Mazzie and Jason Danieley
- The Fight to Eliminate Cancer: An Inside Look at the Cancer Moonshot

Frankly Speaking About Cancer is made possible through generous support from Amgen Oncology; Astellas Pharma US, Inc.; AstraZeneca; Bristol-Myers Squibb; Celgene Corporation; Eisai Inc.; Incyte Corporation; Janssen Oncology and Pharmacyclics Inc., Lilly Oncology; Medivation Inc.; Myriad Genetics Inc.; PhRMA; and Takeda Oncology.

Launching Frankly Speaking About Cancer Clinical Trials Program

In June 2016, the Cancer Support Community published *Frankly Speaking About Cancer Clinical Trials,* which uses patient and caregiver stories to discuss key information about clinical trials. After gathering robust patient feedback during the pre-publication phase, materials were then developed to more fully incorporate the complete patient experience as a way to dispel myths about clinical trials and to increase awareness and participation. Though clinical trials are designed to provide research essentials to developing innovative cancer treatments, less than 5% of eligible adults with cancer participate in them. This new program in our series encourages cancer patients to consider clinical trials as a viable treatment option throughout their cancer journey.

Materials include:

- Research report raising awareness of current patient perceptions of clinical trials
- Photo narrative outlining crucial considerations about clinical trials
- Video of real conversations between patients, their families, and their health care teams about clinical trials
- Fact sheets available in English and Spanish
- New webinars hosted on CSC website
- Live workshops hosted at local CSCs and Gilda's Clubs

For more information on **Frankly Speaking About Cancer Clinical Trials**, visit www.CancerSupportCommunity.org/ClinicalTrials.

Empowering Patients: CancerEd Online

CancerEd Online is a new interactive educational series for cancer patients, survivors, and caregivers. These brief online courses cover what patients need to know about topics like self-advocacy, new ways of managing cancer care, cancer treatment guidelines, clinical pathways, bundled payments, precision medicine, oncology medical homes, and accountable care organizations. To take current courses and to explore new courses being added monthly, visit: www.CancerSupportCommunity.org/CancerEd.

Thanks to Amgen Oncology, Bristol-Myers Squibb, Celgene Corporation, and Genentech for making CancerEd Online possible.



Frankly Speaking About Cancer Clinical Trials Receives White House Recognition and Health Award

FRANKLY SPEAKING ABOUT CANCER CLINICAL TRIALS REACHES CANCER MOONSHOT The Cancer Support Community is supporting the Cancer Moonshot goal of making a decade's worth of cancer research progress in just five years. CSC is proud to have Frankly Speaking About Cancer Clinical Trials incorporated into the official set of resources made available to patients and clinicians as part of the White House's Cancer Moonshot initiative.

FRANKLY SPEAKING ABOUT CANCER CLINICAL TRIALS WINS DIGITAL HEALTH AWARD The photo novella created as part of the Frankly Speaking About Cancer Clinical Trials program was awarded a Fall 2016 Digital Health Award, which honors the world's best digital health resources.

To find out more, visit www.CancerSupportCommunity. org/ClinicalTrials.

Thank You to Our 2016 Donors

Collegium

Pharmaceutical

The list below includes gifts and grants received in 2016. The Cancer Support Community has done its best to accurately acknowledge each of our valued contributors. If we have inadvertently omitted or misspelled your name, please let us know.

\$500,000 AND ABOVE

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Thank you so very much for helping and taking the time to talk with me today. I cannot express in words how much it means to me that someone is listening and cares.

-Cancer Support Helpline caller

CALLERS' TOP AREAS OF CONCERN:

- · Coping with emotions
- Financial or insurance issues
- Locating additional support services close to home

NEW COUNSELORS ADDED IN:

- Pediatric Cancer
- Financial Navigation
- Clinical Trials
- Genetic Counseling



HOPE

Providing Support through the Cancer Support Helpline[®]

People touched by cancer are increasingly seeking personal navigation services by telephone. The human touch of connecting with a supportive and trained health professional is critical to improving quality of life, and allowing patients to more effectively work

through the challenges of cancer, such as treatment and survivorship. In 2016, the *Cancer Support Helpline* (open 9am-9pm, Eastern Time, Monday-Friday) fielded nearly 18,000 phone calls



from patients, families, and health professionals seeking information, access to local and national resources, and supportive counseling.

Thanks to the American Psychosocial Oncology Society, Amgen Oncology, Bristol-Myers Squibb, Eisai Inc., Fight Colorectal Cancer, Genentech Inc., Incyte Corporation, Joe's House, Lung Cancer Alliance, Pfizer, and Seattle Genetics for their support of the *Cancer Support Helpline*.

Expanding Magnolia Meals at Home

CSC continued its partnership with the Meals on Wheels Association of America, CancerCare, and Cornucopia Cancer Support Center to deliver meals to people receiving cancer treatment. Over 1,400 eligible families in and around three cities in New Jersey, Massachusetts, and North Carolina received up to six months of meals. In 2016, the program expanded to include not only people living with breast cancer, but also diagnoses of thyroid, soft tissue sarcoma, and kidney cancers. This project helps provide healthy, balanced meals designed to meet the dietary needs of people being treated for cancer, while also appealing to the patient's entire family or household.

This project was funded by Magnolia and the Eisai Women's Oncology Program.

Preparing Patients to Make Better Treatment Decisions



As breakthroughs in cancer research are leading to more targeted treatment, patients are increasingly presented with more complex options. They are sifting through complicated information from multiple sources, and many are unsure of what questions to ask. At the same time, physicians are unsure about what patients understand about their diagnosis or treatment options. Health care professionals also appreciate any tool that will help focus the discussion on the treatment decision at hand.

CSC's signature *Open to Options*[®] treatment decision support program continues to expand across CSC Affiliates and the **Cancer Support Helpline**. Thanks to a grant from Bristol-Myers Squibb, CSC conducted extensive outreach in 2016, promoting the program and initiating regional training for CSC affiliates, while also exploring how patients and providers perceive decision support needs around advanced care planning and end-of-life discussions.

CSC was also pleased to join with Anthem and Genentech to create and launch a related online program called Let's Talk Treatment Options: <u>www.</u> <u>talkingtreatment.org.</u> This web-based application takes patients through a six-step process designed to help them organize their thoughts and questions into a personalized question list for their doctor. Now, people seeking to improve communication about treatment issues can access this program at anytime online. CSC is committed to patient empowerment and shared decision-making across the continuum of care, and Cancer Support Helpline counselors are trained to assist callers in preparing their personalized question list to take to their doctors. This is a critical step in preparing patients to engage in a meaningful discussion with their doctors about the next steps of care. Special thanks to Anthem and Genentech, Inc. who share CSC's commitment to patient empowerment and shared decision-making.





THE 2016 AFFILIATE LEADERSHIP CONFERENCE WAS SUPPORTED BY THE FOLLOWING SPONSORS:

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Connecting through our Affiliate Network

The Cancer Support Community's Affiliate Network consists of 42 centers, 150 satellite locations, a growing number of hospital partnerships, and federally qualified health center partnerships. The Cancer Support Community and Gilda's Club Affiliates deliver high-quality, evidence-based psychosocial support for anyone impacted by cancer. Programming includes educational workshops, support groups, short-term individual counseling, health and wellness programs, social activities, and resource and referral services. In 2016, more than 90,000 people made approximately a million visits to our locations. All programs at all locations in the network are free of charge to anyone affected by cancer, including patients, caregivers, loved ones, and children. The value of these free services provided by the CSC network each year (in addition to volunteer services) totals in excess of \$50 million.

In 2016, CSC hosted its annual Affiliate Leadership Conference in Detroit, Michigan. CSC Affiliate staff leadership from across the United States and Canada attended multiple education and networking sessions on topics critically important to the patients and families whom they serve every day.

Also at the conference, seven Affiliates were recognized with the **Affiliate of Distinction** honor as a result of their performance under the Cancer Support Community's Continuous Quality Improvement (CQI) initiative. CQI recognizes excellence in program delivery, administration, fundraising, governance, and communications. Congratulations to the following Affiliates for achieving this significant milestone:

- CSC Ann Arbor
- CSC East Tennessee
- CSC Massachusetts
 South Shore
- CSC Redondo Beach
- Gilda's Club Quad Cities
- Gilda's Club Rochester
- · Gilda's Club South Florida

I am so impressed and thankful that this happened! The information was provided in a way that was so easy to understand from a patient's perspective. This was the first time I have ever met someone with my diagnosis. Thank you from the bottom of my heart.

-Attendee at a CSC MPN Awareness Event

Shining the Light on Myeloproliferative Neoplasms (MPN)

During September 2016's Blood Cancer Awareness Month, CSC offered support and education to the MPN community through awareness events hosted by five of our local centers. Post-event surveys indicated approximately 96% of attendees surveyed would recommend these events to someone impacted by an MPN. In addition, the most important benefits, as cited by participants, were increased knowledge about MPNs and connecting with others.

This project also included the development of a new *Frankly Speaking About Cancer* initiative: 10 *Tips to Living Well with MPN,* which includes a pamphlet, a radio show, and a series of video interviews with MPN patients and caregivers about their tips for "living well."

This program was funded by Incyte Corporation.



Myeloproliferative Neoplasms (MPN)

Reaching out with Facebook Live & Twitter Chats

The Cancer Support Community engages social media followers through live events such as Twitter Chats and Facebook Live videos, where patients, caregivers, and advocates can interact with experts and participate in real-time discussions on a variety of cancer-related topics. Through Facebook Live, Cancer Support Community's online followers were able to virtually participate in the June 2016 Cancer Moonshot Summit events and hear from White House leaders, patients, and medical experts.



Assisting People Touched by Lung Cancer with Transportation

The Transportation Assistance Program provides muchneeded travel assistance to people living with metastatic lung cancer. In 2016, CSC provided more than 400 gas cards to patients in need of transportation assistance, while also linking patients with support and referral services.

This program is a collaborative partnership between the Lung Cancer Alliance and CSC, and is made possible by Bristol-Myers Squibb.

Screening for Distress

People impacted by cancer who visit a CSC Affiliate or call the **Cancer Support Helpline**, no matter where they are in the cancer journey, can benefit from CSC's comprehensive, electronic, validated distress screening program, CancerSupportSource[®].

Once the brief screening survey is completed, CSC experts help patients develop a personal support care plan to address their fears and concerns, and find resources to help. As cancer care providers across the country continue to partner with CSC to better meet the needs of their patients, they are also using CancerSupportSource to meet various accreditation and quality care standards.

In 2015, the Cancer Support Community was the beneficiary of the Celgene Innovation Impact Award for developing a model program to optimize the patient experience during a clinical trial by reducing the stress involved in choosing or participating in a trial. Throughout 2016, CSC gathered focus group information from patients and caregivers about what was important to them as they considered or participated in a clinical trial. The model also includes our award-winning Frankly Speaking About Cancer Clinical Trials educational materials, the Open to Options treatment decision support program, which helps patients talk about clinical trials with their doctors, and information about distress screening, which could lead to improved recruitment, retention, and overall satisfaction with the clinical trial experience.

Community

Participating in **Breakaway from Cancer**

For more than a decade, the Cancer Support Community has been a proud partner of **Breakaway from Cancer**, a national initiative founded by Amgen Oncology to raise awareness—through media coverage, online exposure, professional meetings, and nationwide events of the resources available to people impacted by cancer. Thousands of people attended events across the country in 2016 and gained access to information, support, and resources to help them navigate their personal cancer journey. The most notable events included the Amgen Tour of California cycling race and the Dempsey Challenge, a weekend of wellness activities that included a walk, run, and bike race, in Lewiston, Maine. Participants also engaged in online, telephone, and social media activities throughout the year.

The Cancer Support Community is grateful to work alongside Breakaway from Cancer partners the National Coalition for Cancer Survivorship, the Patient Advocate Foundation, the Prevent Cancer Foundation, and Amgen Oncology.

Spreading Awareness with #4Chords4Cancer

A community of musicians and music lovers from around the world came together in 2016 to spread awareness through social media of the free resources available to people with cancer and their loved ones.

The Cancer Support Community partnered with Healtheo360, an online patient and caregiver community, to implement **#4Chords4Cancer**. Beginning in the spring, a custom-designed acoustic guitar made its way across the United States gathering autographs and stories of musicians who share our belief that no one should have to face cancer alone. Anyone was invited to participate by photographing or recording themselves playing four chords on an instrument of their choice, then sharing via Twitter, Instagram, or Facebook using the hashtag #4Chords4Cancer.

After gathering the signatures of Lynyrd Skynyrd, Sara Bareilles, Peter Yarrow of *Peter, Paul and Mary*, the cast of ABC's "Nashville," and the Broadway cast of *School of Rock*, among others, the guitar was auctioned off at CSC's 2016 Spring Celebration gala to raise vital funds in support of a range of CSC programs.

This project was made possible thanks to the generous donations of Dave Nichols of Custom Pearl Inlay, Healtheo360, Martin Guitar, and Ogilvy Public Relations.

CHORDS 4 CANCER

This is MY

Celebrating the Cancer Community: The 2016 Spring Celebration

Each year, the Cancer Support Community's annual Spring Celebration recognizes heroes in the cancer community while raising vital funds to advance CSC's mission. Highlights of the 2016 event were the presentation of the #4Chords4Cancer guitar, a special musical performance by Broadway star LaChanze, and the presentation of three awards honoring Harold and Harriet Benjamin, founders of The Wellness Community, and Joanna Bull, founder of Gilda's Club Worldwide.

In addition, three Founders Awards were presented to the following individuals for their tireless work on patient advocacy, clinical advancements, and raising awareness.

The **Founders Award for Spirit** recipient was Katherine Kelly Lang, an actress from "The Bold and the Beautiful" and an Ambassador for Amgen's Breakaway from Cancer Initiative. Kelly can be found walking alongside survivors in celebration walks, signing autographs for fans, creating new kaftan designs to benefit cancer charities, and supporting many through her social media engagement.

The **Founders Award for Innovation** was given to Pfizer Oncology for their commitment to the discovery, investigation, and development of innovative treatment options. They deliver meaningful therapies that transform the cancer treatment landscape and translate innovative science into breakthrough medicines.

The **Founders Award for Empowerment** celebrated Marin Mazzie and Jason Danieley, who are known as "Broadway's Golden Couple." When Marin was diagnosed with ovarian cancer in 2015, Marin and Jason found themselves in very different roles. Through Marin's optimism and Jason's unfailing support, they embraced these roles and learned how to work together to lift, educate, and strengthen one another. Through advocacy and outreach, they have become a beacon of empowerment for so many people.

Singing with a Purpose with John Riddle and Barbara Bradley Baekgaard

In December 2016, Barbara Bradley Baekgaard, co-founder of retailer Vera Bradley, hosted a private concert with Broadway star John Riddle at her home in New York City to help raise awareness and vital funds for CSC, doing their part to ensure that no one faces cancer alone. Thank you to John for his performance and to our Broadway Series hosts who helped make this event a success:

- Barbara Bradley Baekgaard
- Joanie and Bob Hall
- Jill and Tom Durovsik
- Lauren and Aaron Barnes
- Michael Goddard and Shane Hoffman

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TRI-ing with Team CSC!

On September 11, 2016, Team CSC competed in the annual Nation's Triathlon in Washington, D.C. to help raise money to support people impacted by cancer. This was the second consecutive year Team CSC participated, and we nearly doubled our size and fundraising total. A portion of the proceeds go directly to Whitman Walker Health to help support the CSC programs provided at their clinic.

For more information on how to join or support Team CSC in 2017 visit: <u>cancersupportcommunity</u>. <u>org/2017-nations-triathlon</u>.





THANK YOU TO OUR 2016 TEAM CSC ATHLETES WHO HELPED US TO REACH THIS GOAL:

Julie Billingsley (Coach) Jami Fancher John Friend Meredith Gardner Rob Goldsmith Jennifer Griola Linda House Chelsea Johnson Michelle Johnson

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Donor Spotlight: Michelle Joubran

In 1997, Michelle Joubran competed in her first triathlon event. She was hooked and made an effort to compete in triathlons regularly. Two years ago, Michelle was involved in a serious cycling accident, causing severe injuries that prevented her from competing regularly in races. In 2016, Michelle's friends challenged her to join Team CSC and compete in her first Olympic-distance triathlon since the accident. Michelle agreed and became a vital member of Team CSC in the Nation's Triathlon. She was impacted by cancer on several fronts and was motivated to help our cause and mission.

Michelle's close college friend Darren was diagnosed with stage 4 colorectal cancer in 2015. Darren and his family had to leave their Florida home to spend a year at Johns Hopkins Hospital in Maryland to get the treatment he needed. Darren fought hard and beat the odds, and is now living in Florida as a cancer survivor.

With Darren's inspiring story in mind, Michelle spoke with Courtenay Labson, fellow Team CSC athlete, about ways she could start fundraising. Courtenay told Michelle that she was matching all of the donations her friends and family were making to her race. Michelle loved the idea and the two of them took a pledge to match all of the contributions that came in on their behalf. Michelle's fundraising took off faster than she expected. Her friends and family came together to give well over her original fundraising goal, which Michelle then very generously doubled.

"This was the most fun triathlon I had ever competed in! It was for a good cause and I was able to cross the finish line hand in hand with one of my good friends, Libby Mullin," says Michelle.

The Cancer Support Community would like to thank Michelle for all of her hard work in her training and fundraising. People like Michelle, Courtenay, and Libby are the strength behind CSC and help motivate us to continue to work to ensure that no one faces cancer alone.



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Shauna McManus, Coordinator, Research

Nick Power, Coordinator, Strategic Initiatives

Christina Raia, Director, Corporate Development

Kristen Santiago, Senior Director, Policy & Advocacy

Claire Saxton, Senior Director, Education

Jenny Song, Director, Digital & Web

Sarah Suettinger, Manager, Administration

Allison Sypher, MA, Fellow, Cancer Policy Institute

Jeff Travers, Executive Vice President, Finance & Administration

Alexandra Zaleta, PhD, Director, Research

CSC Recognition

GuideStar USA, Inc.'s mission is to revolutionize philanthropy and nonprofit practice by providing information that advances transparency, enables donors to make better decisions, and encourages charitable giving. CSC was honored to earn the GuideStar Exchange Platinum Participant distinction in 2016. This is the highest level of participation that a nonprofit can achieve through the GuideStar exchange and is a testament to our organization's commitment to data transparency.

We were honored to, again, be given four stars, the highest rating, by **Charity Navigator**. The rating is awarded based on the quality and effectiveness of programs and services as well as the way an organization functions financially.

We are proud to have received the **Independent Charities Seal of Excellence**, awarded to organizations that meet the highest standard of public accountability, program effectiveness, and cost effectiveness. Of the roughly 1 million charities operating in the United States today, it is estimated that fewer than 50,000, or 5%, meet or exceed these standards; and of those, fewer than 2,000 have been awarded a Seal of Excellence.

CSC was honored to be named as a **Top Nonprofit Organization** by **Philanthropedia**. This designation was based on a survey of experts in the field of cancer care who were asked to rank organizations specifically by their degree of positive impact on people touched by cancer.

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Ways to Give

The work of the Cancer Support Community is made possible through generous contributions from individuals, as well as sponsorships and grants from corporations and foundations. Unrestricted gifts offer the greatest flexibility in carrying out our mission. Every gift is important, and there are several ways to donate:

Online, Mail, or Phone

Visit our website at <u>www.cancersupportcommunity.org</u> and click "Donate" to give using a credit card. Or send a check to:

Cancer Support Community 734 15th Street, NW Suite 300 Washington D.C. 20005

We also welcome the opportunity to speak with you. Please call us at 202-659-9709.

Shopping in Our Marketplace

At CSC's Marketplace, purchase unique, one-of-a-kind items to raise funds for CSC programs and activities. These include John Wind Maximal Art jewelry, customizable Bravelets, Pour le Monde perfume, and more. CSC also partners with Amazon Smile, Goodsearch/GoodShop to turn ordinary online purchases on those websites into an automatic donation for CSC. Visit <u>www.</u> <u>cancersupportcommunity.org/shop-csc</u> to shop our Marketplace and register for Goodsearch/GoodShop.

Creating your Own Fundraising Campaign

Be part of a passionate community of supporters by starting a fundraising campaign of your own. Run a marathon, celebrate a birthday, or fundraise with your classroom. Start your campaign by visiting: <u>www.cancersupportcommunity.</u> <u>org/make-difference</u>.

Volunteering

Providing support to all people touched by cancer is at the core of everything CSC does. Strong, outspoken, and engaged volunteers strengthen our efforts to ensure that no one faces cancer alone. For volunteer opportunities, visit www.cancersupportcommunity.org/volunteer.

Purchasing a Memorial or Tribute Bench or Brick

The Cancer Support Community's Research and Training Institute is located in historic Fairmount Park in Philadelphia. The Institute's uniquely designed building and picturesque property feature reflective gardens and ambling pathways that offer hope, healing, and peace. An inscribed brick or bench on the patio of the Research and Training Institute is a wonderful way to honor or celebrate someone, while also helping the Cancer Support Community ensure that no one faces cancer alone. To help create a lasting legacy in honor of or in memory of a loved one through our Tribute Bricks and Benches program, call **202-659-9709** for more information or email us at **development**@**cancersupportcommunity.org**.

Making a Tribute and Memorial Gifts

Use any of the above methods to make a gift in honor of or in memory of a special person or occasion. CSC will acknowledge your contribution and notify the honoree or family that a tribute or memorial gift has been made in their name.

Federal Appeals

(For Government Employees)

Federal employees will find Cancer Support Community listed as an option in the alphabetical index of the Combined Federal Campaign (Combined Federal Campaign number 11674).

Workplace Giving

(Non-Government Employees)

Many companies have giving programs (e.g., United Way) that make donating easy. Please check with your company for more information.

Matching Gifts

Increase your donation with employer matching funds. Please check with your company.

Stock Gifts

Gifts of stock can be a preferred method for some making charitable contributions. Please call CSC at **202-659-9709** for information about transferring stocks.

Cars and Other Vehicles

Thinking about selling your car, boat, motorcycle, truck, or other vehicle? Donate it to CSC instead. All you need is a clear title, and we will take care of the rest, including pick-up, at no cost to you. Once your vehicle has been sold, you will be sent a receipt for your tax records, and any proceeds will be donated to CSC in your name. Learn more about the vehicle donation program by calling **1-877-272-5650** or visiting http://www.cancersupportcommunity.org/ways-give.

Legacy and Planned Giving

Leave a generous legacy by designating CSC as a beneficiary in your will. Your attorney or tax advisor can provide guidance. To speak with us about naming CSC as a beneficiary, please call **202-659-9709**.

Financial Report

This statement reflects the activities of the Headquarters organization. Across the Network, CSC is a nearly \$50 million organization.

5%

PATIENT PLANNING SERVICES 4%

Consolidated Statement of Activities

STATEMENT OF ACTIVITIES, YEAR ENDED DECEMBER 31, 2016

	UNRESTRICTED	TEMPORARILY RESTRICTED	PERMANENTLY RESTRICTED	TOTAL	EXPENSES	
REVENUES AND OTHER SUPPORT						
Development Income	\$ 454,514	-	-	\$ 454,514		
Interest Income	59,580	-	-	59,580		
Unrealized Gain of Investments	48,355	-	-	48,355		
SERVICE DELIVERY						
Program	130,755	2,136,316	-	2,267,071		
Research and Training	296,145	463,683	-	759,828		
Events and Special Initiatives	826,371	-	-	826,371		
Less Direct Expenses	(269,446)	-	-	(269,446)		
Digital Services and Web	50,000	110,000	-	160,000		
Education/Outreach	45,988	832,697	-	878,685		
Policy/Advocacy	1,010,731	383,429	-	1,394,160	PROGRAMS AND SERVICES	
Affiliate Activities	687,994	-	-	687,994		
Communications	11,500	-	-	11,500		
In-kind Revenue	53,770	-	-	53,770		
Miscellaneous Income	54,075	-	-	54,075		
Patient Planning Services Sales, Net of Direct Costs of \$21,667	234,541	-	-	234,541		
Net Assets Released from Restriction	3,112,665	(3,112,665)	-	-		
Total Revenues and Support	\$ 6,807,538	\$ 813,460	-	\$ 7,620,998		
EXPENSES						
Program Services	6,315,059	-	-	6,315,059		
Management and General	487,496	-	-	487,496		
Fundraising	359,303	-	-	359,303		
Operating Expenses: PPS	314,466	-	-	314,466		
Total Expenses	\$ 7,476,324	-	-	\$ 7,476,324		
Change in Net Assets	\$ (668,786)	\$ 813,460	-	\$ 144,674	MANAGEMENT	
Net Assets at Beginning of Year	\$ 4,142,347	\$ 5,351,782	\$ 10,000	\$ 9,504,129	AND GENERAL	
Net Assets at End of Year	\$ 3,473,561	\$ 6,165,242	\$ 10,000	\$ 9,648,803	7%	

Cancer Support Community is a 501 (c) (3) charitable organization and all donations are tax-deductible to the extent allowed by the law. Every gift to the Cancer Support Community helps us ensure that no one faces cancer alone. We thank you for your generous support.

Patient Planning Services (PPS) is a subsidiary controlled by CSC that licenses certain CSC products and services to hospitals and other external partners.





165 West 46th Street, Suite 1002 New York, NY 10036 Phone: 917.305.1200 Fax: 212.967.8717

RESEARCH AND TRAINING INSTITUTE

4100 Chamounix Drive, Philadelphia, PA 19131-3724 Phone: 267.295.3000 Fax: 215.882.1580