



# REDEFINING THE CANCER EXPERIENCE

## 2015 ANNUAL REPORT



**CANCER SUPPORT  
COMMUNITY**

*A Global Network of Education and Hope*

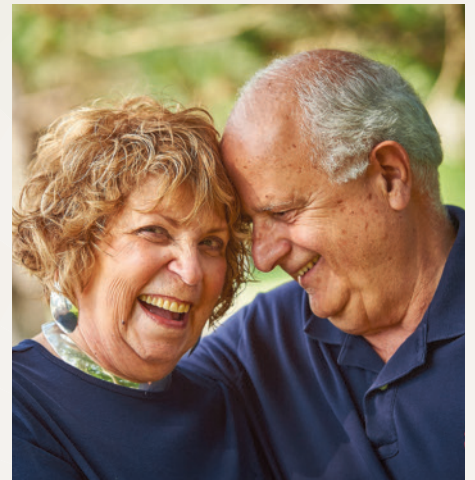


**the  
wellness  
community**

## 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 advocacy. 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 patient advocacy 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](http://CancerSupportCommunity.org).

*So that no one faces cancer alone.®*



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## Dear Friends of the Cancer Support Community,

Thank you for your allowing us to be part of your journey, for your continued support and most of all, for your dedication to redefining the cancer experience.

2015 was a landmark year for the Cancer Support Community—a year in which we as an organization saw tremendous growth, and we as a community saw tremendous change in the cancer experience.

These changes in the patient experience lead to a new vision where we as a community evolved from the idea of keeping patients at the center of their care to the practice of actively working with patients in *directing* their care. In a world with patient-*directed* care, people living with cancer are instilled with a sense of empowerment to advocate for themselves and have the knowledge needed to make informed decisions about their treatment and care alongside their health care team.

To achieve this vision of patient-directed care, we must create solutions for some of the greatest needs facing people who are living with cancer today, such as the need for more insight into the patient and caregiver experience, more educational and supportive resources about the cancer experience, and transparency between patients and their health care teams.

The health care community needs a deeper insight into the true patient and caregiver experience in order to provide people with the highest quality care. This means learning more about the physical, emotional, social and financial impact of cancer. Our **Research and Training Institute** continues to learn more from the *Cancer Experience Registry* to develop this much-needed insight, share it with the cancer community, and in turn, redefine the cancer experience.

People impacted by cancer need more access to information about the price and quality of their care in order to make informed decisions. Our **Cancer Policy Institute** is working directly with policymakers and advocates to create a system of transparency so that all patients have access to high-quality, comprehensive cancer care that includes social and emotional support.

Currently there are more than 14 million cancer survivors living in the United States. By the year 2022, that number is expected to grow to more than 18 million. However, the number of health care professionals in the United States is not expected to increase at a comparable rate, creating a need for services to be delivered outside the physician's office that will improve the lives of people living with cancer. Our Affiliate Network, *Cancer Support Helpline*, distress screening tool and educational resources provided through our *Frankly Speaking About Cancer* programs are doing exactly that. By creating patient communities in person, online and over the phone, we are giving patients more opportunities to be drivers of their own cancer care.

These are just a few of the ways we are working to continue to improve the cancer journey. Redefining the cancer experience so that care is patient-driven will not be easy, but it is certainly possible. And we are working every day to achieve that vision.

Warmest regards,



Kim Thiboldeaux  
Chief Executive Officer



Jill Durovsik  
Board Chair



FACEBOOK  
**114%**  
GROWTH

TWITTER  
**29%**  
GROWTH

LINKEDIN  
**73%**  
GROWTH

INSTAGRAM  
**145**  
FOLLOWERS  
LAUNCHED IN AUGUST

PINTEREST  
**30%**  
GROWTH

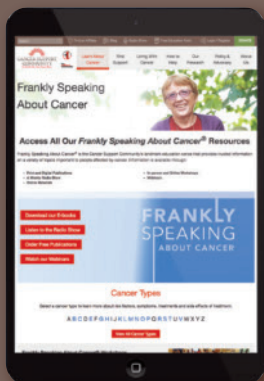
CSC BLOG SESSIONS  
**42%**  
INCREASE



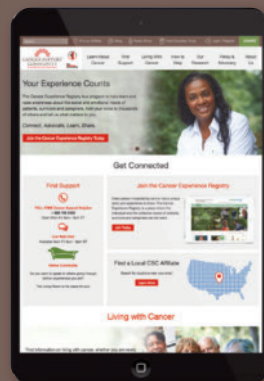
**4.16 BILLION PEOPLE REACHED FROM 2015 MEDIA MENTIONS**

**#CSCEMPOWER CAMPAIGN REACHED**

**8.25 MILLION PEOPLE**



**2,449**  
FSAC PROGRAM  
PARTICIPANTS



**251,617**  
WEBPAGE  
VIEWS



**71,221**  
FRANKLY SPEAKING ABOUT  
CANCER MATERIALS DISTRIBUTED



**99%**  
INCREASE IN CALLS  
TO THE CANCER  
SUPPORT HELPLINE

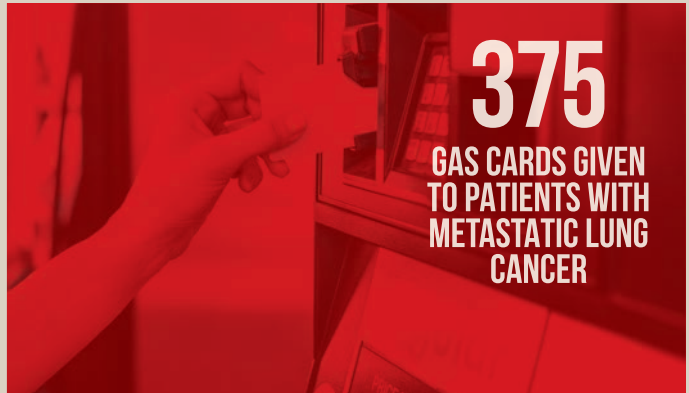


**78%**  
INCREASE IN UNIQUE  
CALLERS TO THE  
CANCER SUPPORT  
HELPLINE

PROGRAMS



**33,600**  
VISITS TO ONLINE  
SUPPORT GROUPS  
IN 2015



**375**  
GAS CARDS GIVEN  
TO PATIENTS WITH  
METASTATIC LUNG  
CANCER

				
<b>44</b>	<b>3</b>	<b>7</b>	<b>120</b>	<b>332</b>
OPEN AFFILIATES	AFFILIATES IN DEVELOPMENT	HOSPITAL PARTNERSHIPS	SATELLITE LOCATIONS	LICENSED MENTAL HEALTH PROFESSIONALS

CSC AFFILIATE NETWORK



**60,000**  
CANCER  
INSURANCE  
CHECKLIST  
DOWNLOADS

MORE THAN  
**1,000**  
GRASSROOTS  
ADVOCACY NETWORK  
MEMBERS

CANCER POLICY INSTITUTE

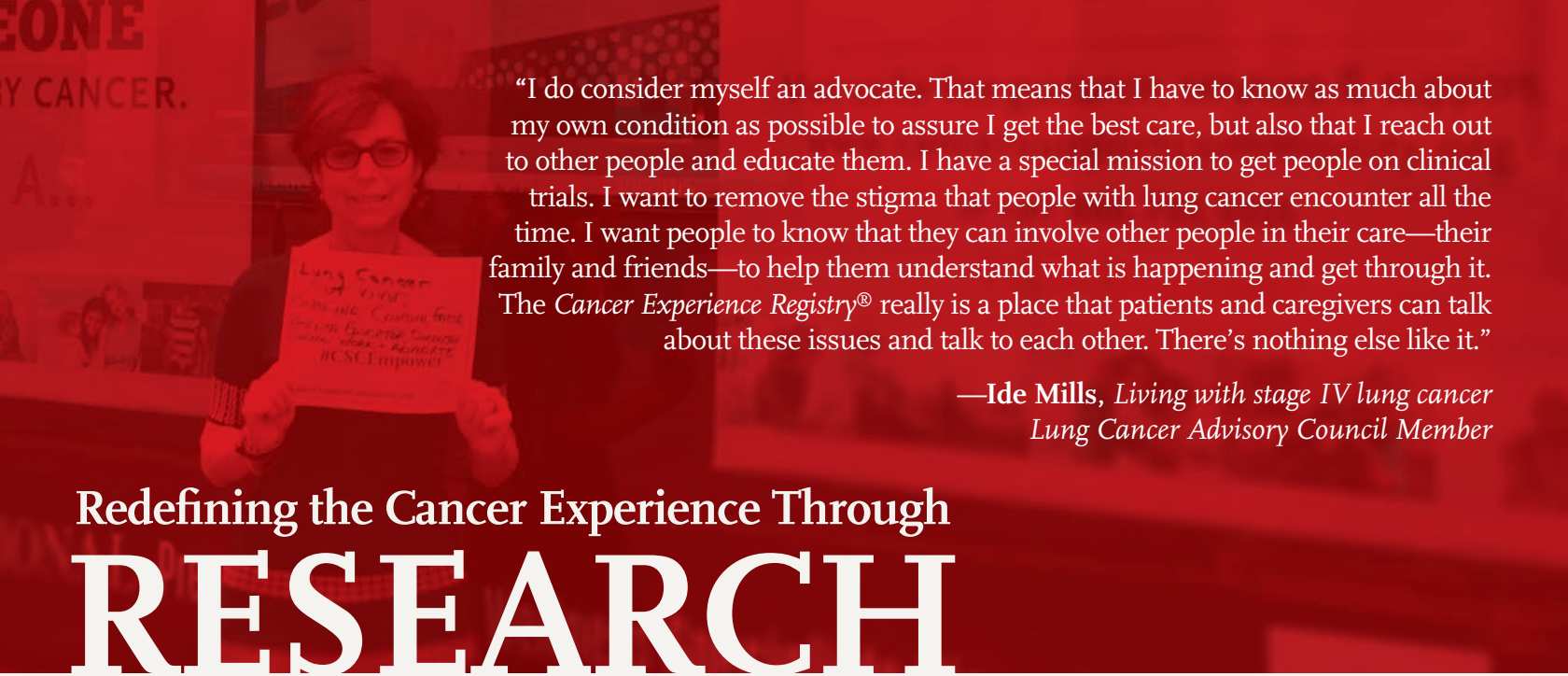


MORE THAN  
**10,000**  
REGISTRY MEMBERS

**11**  
CANCER-SPECIFIC  
REGISTRIES

 **CANCER EXPERIENCE  
REGISTRY**  
A PROGRAM of the CANCER SUPPORT COMMUNITY

CANCER EXPERIENCE REGISTRY



“I do consider myself an advocate. That means that I have to know as much about my own condition as possible to assure I get the best care, but also that I reach out to other people and educate them. I have a special mission to get people on clinical trials. I want to remove the stigma that people with lung cancer encounter all the time. I want people to know that they can involve other people in their care—their family and friends—to help them understand what is happening and get through it. The *Cancer Experience Registry*® really is a place that patients and caregivers can talk about these issues and talk to each other. There’s nothing else like it.”

—**Ide Mills**, *Living with stage IV lung cancer*  
*Lung Cancer Advisory Council Member*

## Redefining the Cancer Experience Through **RESEARCH**

### Changing the Cancer Experience Through Research

The Cancer Support Community’s robust research initiatives aim to ensure that our programs help people affected by cancer, today and in the future. 2015 was an extraordinary year, marked by the growth and expansion of our community-driven *Cancer Experience Registry*, improvements to our website that make it easier for people to find and share information, presentations to promote the patient voice and progress on a tool to assess caregiver distress. Today, the *Registry* has more than 10,000 members.

### Sharing with the Community

Sharing what we learn with the cancer community is vital to ensuring that the patient voice is used to redefine the cancer experience. In 2015, **Research and Training Institute** staff presented at leading cancer and public health symposia, including the American Society for Clinical Oncology (ASCO) Annual Meeting, ASCO Palliative Care Symposium, the American Society for Hematology, the National Comprehensive Cancer Network, the San Antonio Breast Cancer Symposium, the Society for Behavioral Medicine, the Association for Value-Based Cancer Care and the World Congress of Psycho-Oncology.

Presentations, posters and published peer-reviewed articles addressed critical issues facing patients and caregivers, such as:

- The role of distress screening in doctor-patient communication
- The impact of financial toxicity on emotional health
- Attitudes and beliefs influencing treatment adherence
- The impact of symptom burden on communication about palliative care
- How perceptions of the cancer experience change over time

### Shaping the Future

The Cancer Support Community’s research gives voice to the cancer community in ways only possible through community-initiated research. But that is not enough. Redefining the cancer experience demands that CSC take an active leadership role in communicating what is learned to the larger cancer community and using this knowledge, wisdom and insight to affect real change for patients and their loved ones.

We are grateful to the individuals and organizations that support the **Research and Training Institute** in this mission, including: Amgen Oncology, Bayer, Boehringer Ingelheim, Bristol-Myers Squibb, Celgene Corporation, Genentech Inc., Helsinn, Janssen, Lilly Oncology, Pfizer, Pharmacyclics, Inc. and PhRMA.



## Growing the Cancer Experience Registry

The Cancer Support Community's *Cancer Experience Registry* enables people with cancer to make their voices heard, connect with each other and identify issues related to the realities of living with cancer. This unique resource gains strength from the number of people who participate and the depth of the information shared. For these reasons, growing the *Registry* is a high priority. Growth means more participants and information but also means expanding the pathways used to share findings with the community. Improvements to the CSC website in 2015 make it easier for *Registry* participants to register, customize their experience, receive updates and connect with others.

The information we learn from the *Registry* benefits patients and their families in several ways. Our findings are used to develop and improve programs and services, address gaps in patient care and inform policy. In 2015, data collected through the *Registry* played a key role in the development of new *Frankly Speaking about Cancer*® programs and a major CSC initiative to increase enrollment in clinical trials. Registry data also informed planning of an innovative weekend-long workshop for melanoma patients and caregivers to help them define their personal advocacy agendas.

A growing focus on Specialty Registries helps us better understand the challenges facing individuals with specific cancers and develop targeted resources for these communities. For example, people with lung cancer may be managing the uncertainty of remarkable new treatments that extend life but do not offer a cure. The Specialty Registry for caregivers

recognizes that caregiver needs are often unmet, and their voices unheard. Less common cancers affect fewer people but can be as complex in the questions they raise. People with gastric cancers may feel isolated and have difficulty finding others with similar experiences. These Specialty Registries address the unique shared experiences of people with specific kinds of cancer.

### SPECIALTY REGISTRIES

- Breast cancer
- Caregivers
- Chronic lymphocytic leukemia
- Chronic myeloid leukemia
- Lung cancer
- Melanoma
- Metastatic breast cancer
- Multiple myeloma
- Multiple myeloma caregivers
- Prostate cancer
- Stomach (gastric) cancer

## Understanding Caregiver Distress

Research has shown that caregivers have a tremendous need for appropriate, effective and timely supportive care services. Yet, no proven community-based distress screening and referral programs exist for cancer caregivers. In 2015, the **Research and Training Institute** conducted a study to validate a web-based distress-screening tool for family members and loved ones caring for someone living with cancer. This is the first step in building *CancerSupportSource*® (CSS) for caregivers—making much-needed distress screening, referral and follow-up care available to the whole family.

“I was so desperate that day. Looking back over my life, that day was the lowest I have ever been. I was so frightened. And then I dialed your number. I heard your words loud and clear, whenever things got really bad for me. Thank you so much for those words. So many days and nights I would lay in bed with those words ringing in my head. They encouraged me to get up and push through. May God bless and keep you forever. I will never forget you and hope to shake your hand and give you a great big hug one day.”

—Cancer Support Helpline caller

## Redefining the Cancer Experience Through **SUPPORT**

### Just a Phone Call Away: Helpline Offers Support and Resources

A diagnosis of cancer can lead to many emotions and even more questions. The Cancer Support Community's *Cancer Support Helpline*® is here for everyone affected by cancer, offering answers to questions, connections to resources and a supportive ear. Staffed by licensed mental health professionals, the helpline is open Monday through Friday from 9:00 a.m. to 9:00 p.m. Eastern Standard Time.

In 2015, more people than ever before turned to the *Cancer Support Helpline* for support and information. *Helpline* staff handled nearly 18,000 calls from more than 7,600 unique callers—a 99% increase in total call activity and a 78% increase in unique callers over past years. Top areas of concern included coping with emotions, financial or insurance issues and finding support close to home.

The *Helpline* does more than listen. By forming key partnerships with other organizations, the *Helpline* addresses some of callers' most critical needs. Examples of this include a new referral partnership with Fight Colorectal Cancer and the transportation assistance collaboration described in this report. An ongoing relationship with the American

**CANCER SUPPORT  
HELPLINE  
888-793-9355**



*Cancer Support Helpline* staff held their first-ever retreat at the Research and Training Institute in Philadelphia, PA this year.

Psychosocial Oncology Society (APOS) connects people with mental health services in their communities.

Through continued focus on reaching more patients, survivors, caregivers and members of the health care team, the Cancer Support Community is determined to use the *Helpline* to change and improve the cancer experience.

The *Cancer Support Helpline* is possible thanks to sponsorship from Amgen Oncology, Bristol-Myers Squibb, Eisai Inc., Genentech Inc. and Pfizer, and partnerships with APOS, Fight Colorectal Cancer and Joe's House.



## Reaching Those in Distress

Never has there been a more critical time for people with cancer to have tools to help identify and reduce the distress that cancer brings to their lives. For this reason, the Cancer Support Community developed and licenses to hospitals *Cancer Support Source*®, an easy to use, 15-25 item computerized distress screening tool to help people with cancer identify areas of concern and receive personalized, tailored referrals to information and support resources. In 2015, the American College of Surgeons Commission on Cancer adopted distress screening as a newly required standard for its 1,400+ -accredited institutions.

In addition, distress screening, referral and follow-up have become an integral part of CSC programming across the Affiliate Network and through the *Cancer Support Helpline*. New patients benefit from this highly personalized approach to help them create a personal support care plan to reduce distress. In 2015, thousands of people completed distress screenings and custom support care plans. Research is underway to develop a computerized distress screening for caregivers and, thanks to a partnership with the National Institutes of Health, a computerized distress screening game for children and teens with cancer.



Participants of a support group at Gilda's Club Chicago find ways to relax and de-stress.

## Easing the Burden of Transportation Costs

The cost of cancer care can be overwhelming. Hidden costs, such as transportation to and from treatment, add burden and are not covered by insurance. In response to this need, the Cancer Support Community, in partnership with the *Lung Cancer Alliance*, introduced a Transportation Assistance Grant (TAG) program for people in active treatment for metastatic lung cancer. Eligible individuals receive a gas card to help offset the cost of treatment-related travel. In 2015, CSC provided 375 gas cards and connected participants to valuable counseling and referral services.

This partnership is possible thanks to the support of Bristol-Myers Squibb.

## Teaching Self-Advocacy in Treatment Decision-Making

As cancer treatment becomes more complicated and personalized, people at any stage of their cancer experience may feel unprepared to make critical treatment decisions. The Cancer Support Community's *Open to Options*® program offers a powerful tool to help people with cancer organize their thoughts and communicate their unique goals for treatment with their health care team.

Participants report feeling more engaged in the treatment decision-making process, and both patients and physicians say that appointments are more focused on the major issues driving these important decisions.





WHITMAN-WALKER HEALTH

## The Cancer Support Community at Whitman Walker Health

In 2015, the Cancer Support Community at Whitman Walker Health opened its red door in Washington D.C., becoming CSC's first partnership with a federally qualified health center. Patients at Whitman Walker Health can now attend CSC's free support groups and have access to much-needed information and resources. This partnership was commemorated through a launch event at Whitman Walker Health in August.



## Partnering with Hospitals to Expand our Reach

The Cancer Support Community establishes formal partnerships with health care providers around the country to ensure that high-quality cancer support and education reaches more people touched by cancer. By licensing the CSC program model to hospitals, cancer centers and, for the first time this year, federally-qualified health centers, CSC programming is now available to people affected by cancer who might not otherwise find the support and information they need.

This cost-effective, evidence-based psychosocial support program is fast and efficient to implement. In order to assure program quality, CSC provides ongoing training and technical assistance to partner organization staff, so that they are able to:

- Provide high-impact, evidence-based support programs to people affected by cancer within the walls of their own institution;
- Deliver an evidence-based model for patient-centered care; and
- Meet and exceed emerging standards from accrediting bodies like the American College of Surgeons, Commission on Cancer.

### CANCER SUPPORT COMMUNITY HOSPITAL PARTNERS:

Greenville Health System, Greenville, South Carolina

Monmouth Medical Center, Monmouth County, New Jersey

Monmouth Medical Center Southern Campus, Ocean County, New Jersey

OSF Saint Francis Medical Center, Peoria, Illinois

Presbyterian Kaseman Hospital, Albuquerque, New Mexico

UF Health Cancer Center at Orlando Health, Orlando, Florida

Whitman-Walker Health, Washington, D.C.



OSF Saint Francis Medical Center proudly opened their red doors in 2015.



Greenville Health System, CSC's inaugural hospital partnership, has proudly welcomed patients and their loved ones through its red doors since 2012.



At the celebration of their opening in October, the Cancer Support Community at Presbyterian Healthcare Services got off to a fun start!



UF Health Cancer Center at Orlando Health commemorated the 1st anniversary of their opening with a cake and party!



In 2015, we traveled to Japan to celebrate a very important milestone—the 15th anniversary of the opening of the Cancer Support Community Japan.



World Boxing Association middleweight world champion and cancer survivor Daniel Jacobs taught children at a kid's camp at the Cancer Support Community Greater Philadelphia what it means to be a fighter.

## Many Voices Share One Vision

In November, staff and leadership from the Cancer Support Community's Affiliates gathered in Washington, D.C. for "Many Voices, One Vision," the 2015 annual Affiliate Leadership Conference. Participants from the United States and Canada met for one week to discuss best practices, learn new ways to meet the needs of people touched by cancer and hear from acclaimed speakers and visionaries.

Winners of the 2015 "Affiliate of Distinction" were recognized at the conference for their exceptional service. They serve as models for other CSC Affiliates. Congratulations to the 2015 winners:

- Cancer Support Community Atlanta
- Cancer Support Community Greater Lehigh Valley
- Cancer Support Community Greater Philadelphia
- Gilda's Club Louisville
- Gilda's Club Madison

The 2015 Affiliate Leadership Conference was supported by Amgen Oncology, Astellas Pharma US, Inc., AstraZeneca, Bristol-Myers Squibb, Celgene Corporation, Eisai Inc., Genentech Inc., Greenville Health Systems Cancer Institute, Incyte Corporation, Janssen and Pharmacyclics, Inc., Lilly Oncology, Medivation, Myriad Genetics Inc., PhRMA and Takeda Oncology.



“You can feel really alone when you’re diagnosed with cancer and going through treatment. Support is incredible. For me to be able to reach out to others going through a similar situation, and support and encourage them is very important to me.”

—Donna, living with melanoma



## Redefining the Cancer Experience Through

# EDUCATION

### Frankly Speaking About Cancer

The Cancer Support Community’s popular *Frankly Speaking About Cancer* programs address timely issues of importance to patients and families. 2015 was no exception, as patients and caregivers convened in Philadelphia for CSC’s Melanoma Patient Advocate Summit. The summit focused on educating participants on the risk of recurrence, exploring the meaning of survivorship in the face of this risk and discussing tools and resources to help manage the social and emotional impact of cancer. A training component focused on how to advocate for one’s self and others. The sessions were filmed and participants’ stories are featured throughout CSC’s *Frankly Speaking About Cancer: Melanoma* program.



Another new *Frankly Speaking About Cancer* effort highlights clinical trials. Clinical trials are critical to advancing cancer research, yet only 3–4 percent of eligible patients participate. CSC’s new *Frankly Speaking About Cancer Clinical Trials* program builds on research done through the *Cancer Experience Registry* and focuses on raising awareness of clinical trials and communicating the importance of research and its impact on outcomes at both a personal and societal level. This program features in-person workshops, webinars, videos, a photo narrative, fact sheets and online content.

The Cancer Support Community’s education and outreach programs are possible thanks to generous support from Amgen Oncology, AstraZeneca, BioMarin, Bristol-Myers Squibb, Celgene Corporation, Karyopharm, Lilly Oncology, MedImmune, Merck Oncology, Morphotek Inc., Novartis Oncology, Pfizer Oncology and TESARO Inc.



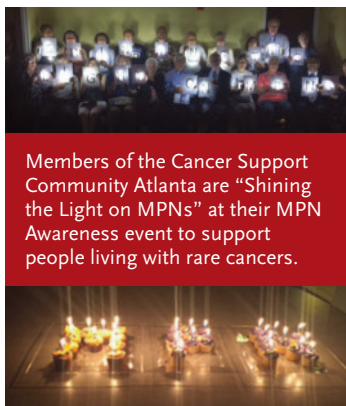
Participants from all over the country convened in Philadelphia, PA for the first-ever Melanoma Patient Advocate Summit. Thank you to all who joined us!

## Shining the Light on a Rare Diagnosis: MPN

Meg had never met anyone with Myeloproliferative neoplasms (MPN) before she attended one of the Cancer Support Community's eight *Shining the Light on MPN* 2015 events. The day featured a physician update and a discussion of the importance of diet and exercise to living well with an MPN. The highlight for Meg was connecting with others with MPN who could understand her experience.

In conjunction with these events, CSC produced a *Frankly Speaking About Cancer* fact sheet on polycythemia vera (a type of MPN) and a *Frankly Speaking About Cancer* radio show episode on living with MPN.

Thanks to Incyte Corporation for making this program possible.

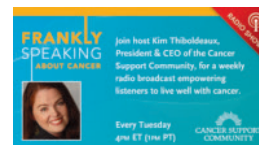


## Find Us Online: New Web-Based Resources

More people than ever before share and receive health information using digital technology. Smartphones, tablets, e-readers and computers provide almost instantaneous access to a wealth of content. A diagnosis of cancer can send many people running to the internet, yet the information they find varies tremendously in quality and accuracy. The Cancer Support Community's webinars, video vignettes, internet radio show and tweet chats address this gap, providing people with high-quality, up-to-date medical and psychosocial information. CSC increased its digital efforts in 2015 and will continue to do so in the coming months and years, to help ensure that reliable, current cancer information reaches and helps more people.

Webinars were an especially exciting focus of the past year. These internet-based presentations address concerns raised at past *Frankly Speaking About Cancer*® programs and through CSC's *Cancer Experience Registry*. Recent webinars addressed nutrition, coping with treatment side effects, balancing work and cancer, managing costs and advances in research, among other topics. All webinars and digital materials are recorded and available on the CSC website.

## Radio Show Empowers Listeners to Live Well with Cancer



Every Tuesday, thousands of listeners tune in to VoiceAmerica to catch *Frankly Speaking About Cancer*, CSC's digital radio show. In 2015, the show featured authors, health care professionals, filmmakers, scientists, television personalities and everyday heroes who shared fascinating stories, helpful tips for living with cancer and information on the latest innovations in cancer treatment. Popular segments included:

- **Patients Raise Their Voices: Joan Lunden and Amy Berman**  
Veteran broadcaster Joan Lunden and Amy Berman of the John A. Hartford Foundation share their inspiring stories to convey the true meaning of patient empowerment.
- **Innovation Happens: A Conversation with Jack Andraka**  
At age 15, Jack Andraka invented an inexpensive early detection test for pancreatic, ovarian and lung cancers. Today this teen is internationally recognized for his role in redefining the cancer experience.
- **Cancer: The Emperor of All Maladies**  
Based on the award-winning book, *Cancer: The Emperor of All Maladies* is a three-part PBS documentary that combines history, science and personal stories. Executive Producer Ken Burns and Director Barak Goodman take listeners inside this critically-acclaimed film.

*Frankly Speaking About Cancer* is available on VoiceAmerica, audioBoom, Blog Talk Radio, iTunes as a downloadable podcast and online at [cancersupportcommunity.org/radio](http://cancersupportcommunity.org/radio).

*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 Pharmaceuticals and Pharmacyclics Inc., Lilly Oncology, Medivation Inc., Myriad Genetics Inc., PhRMA and Takeda Oncology.

“As a two-time cancer survivor, I enjoy working as an advocate in any way possible to bring awareness and comfort to anyone affected by this disease. The Cancer Support Community gives survivors a chance to tell their stories in their own words. By allowing us to speak out, it gives us a great sense of empowerment and control that we have a voice and in our care and in policies that could effect our treatment. Everyone I have met through Cancer Support Community has been so wonderful and committed to making sure no one faces cancer alone! They truly see their work as a calling. I love this organization!”

—Julie Klein, *author of My Healthcare is Killing Me*

## Redefining the Cancer Experience Through **ADVOCACY**

### Making Our Voices Heard

2015 was a meaningful year for the **Cancer Policy Institute** at the Cancer Support Community. Focusing on the core tenets of the **Cancer Policy Institute**—**access** to care for all patients, **quality** as a central theme and **research** as a critical priority—CSC elevates the patient voice and builds skills and awareness across our organization, the Affiliate Network, on Capitol Hill and with individuals and partner organizations within the cancer advocacy community.



### Understanding Barriers to Cancer Care

High-quality cancer care depends on the ability to find, travel to and pay for needed treatments and support services. This year, the Cancer Support Community gathered information on individual experiences accessing care in order to understand barriers to care and better advocate for and support patient needs.



Lee Tomlinson, a participant in the Access to Care study, shared his story at our forum in Washington D.C.

CSC explored the impact of the first full year of the Affordable Care Act on peoples' lives by surveying patients on a range of topics including satisfaction with insurance, access to providers and concerns about cost. An educational event hosted by the **Cancer Policy Institute** in March provided a forum

to report on survey findings and screen a documentary film highlighting disparities in access to care. The survey findings identify gaps in care and stress the need for education on the availability of psychosocial care.

Key findings include:

- 70 percent of patients did not receive social or emotional support services. Half of those did not know that these services existed.
- Nearly 50 percent of respondents reported paying more for health care over the past 12 months.
- Out-of-pocket medical costs remain a top concern for many.

The results of the study were sent to all major U.S. health insurers to consider as they update their benefits packages. More information can be found at: [cancersupportcommunity.org/cancer-policy-institute-events](http://cancersupportcommunity.org/cancer-policy-institute-events).

Thank you to project sponsors Amgen Oncology, Bristol-Myers Squibb, Genentech Inc., Lilly Oncology, Janssen, and Novartis Oncology.

## Using Data to Inform Policy: Defining Value

“What does value mean to me?” A Cancer Support Community (CSC) initiative explores the idea, meaning and impact of “value” in health care. As novel therapies transform length and quality of life for many, questions about financing and approaches to care emerge. Value contributes to treatment decision-making for both patients and health care providers. To better understand the issue, CSC asked 769 people living with metastatic breast cancer how they define value.

The study results show that value has many meanings, and that patients define value differently than policymakers might expect. Less than 5.46 percent of those surveyed saw value as having an economic meaning specific to health. When defining value in health care, approximately 38 percent of patients thought of value in terms of a personal value, emphasizing the importance of their relationship with their health care team rather than the benefits of cost-effective treatment. While quality, efficiency and cost transparency are all essential components of high-quality health care, patients may be more focused on the quality of the doctor–patient relationship than on value related to efficiency or cost.

The findings from this study emphasize the ways in which patients are redefining their cancer experience and making decisions about their care. To learn more about these findings and what they mean, visit [cancersupportcommunity.org/presentations/value](http://cancersupportcommunity.org/presentations/value).

## Get Involved: Join the Grassroots Advocacy Network

The Cancer Support Community’s *Grassroots Advocacy Network* brings together committed individuals to advocate for improved cancer care at the federal, state and local level. The **Cancer Policy Institute** partners with advocates from CSC Affiliates and *Grassroots* members to help people with cancer make their voices heard and work to ensure that everyone has access to comprehensive, quality care.

In 2015, more than 1,000 *Grassroots* members participated in meetings, events and trainings on topics such as prior authorization, funding for the National Institutes of Health and comprehensive care as a part of the 21st Century Cures Act and the Senate Report on Innovations for Healthier Americans.

A new series of webinars armed members with the knowledge and tools to be effective advocates. Titles include: *Grassroots Advocacy 101*, *Creating Access for Patients at the State Level*, *Creating Access for Patients at the Federal Level* and *The Cancer Insurance Checklist*. Special thanks to sponsors Bristol-Myers Squibb and Novartis Oncology for their support of these webinars. Archived versions of webinars can be found at: [www.cancersupportcommunity.org/online-training](http://www.cancersupportcommunity.org/online-training), and to join the *Grassroots Advocacy Network*, please visit [cscadvocate.org](http://cscadvocate.org).

## Working With Regulators: Focus on the FDA

A September meeting brought together members of the cancer advocacy community and representatives of the Food and Drug Administration to better understand how to effectively work together. Expert panelists included key leaders in the FDA, scholars from universities and leading health advocates. The robust conversation touched on topics related to the organization, roles and responsibilities of the FDA, mechanisms for faster approval of new therapies and opportunities for advocacy. Case studies highlighted past collaborations between the FDA and the advocacy community.

Meetings such as this one provide an opportunity for advocates and policymakers to learn from each other,

recognize common goals and develop better ways to work together to improve health care for all. Visit <http://www.cancersupportcommunity.org/events/working-regulators-focus-fda> for more information on this program or to download the tool kit for advocates.

CSC would like to thank our partners for this event, the American Cancer Society Cancer Action Network, COPD Foundation, Friends of Cancer Research, National Alliance on Mental Illness, National Organization for Rare Disorders, National Patient Advocate Foundation and the Society for Women’s Health Research, as well as our event sponsor, GlaxoSmithKline.



Linda House, President, Cancer Support Community; Jill Durovsik, Board Chair, Cancer Support Community; Congressman Steny Hoyer; Libby Mullin, Senior Policy Advisor, Cancer Support Community; Kim Thiboldeaux, CEO, Cancer Support Community.



## It Takes a Team

The **Cancer Policy Institute** at the Cancer Support Community is proud to collaborate with the following partners on key initiatives:

- Alliance for Quality Psychosocial Care
- Alliance for a Stronger FDA
- American College of Surgeons Commission
- C-Change
- Cancer Insurance Checklist Coalition
- Cancer Innovation Coalition/Innovation Working Group
- Cancer Leadership Council
- Center for American Progress Oncology Bundled Payment Consortium
- Coverage Counts
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- Patients Equal Access Coalition
- Patient Quality of Life Coalition
- Regulatory Education and Action for Patients
- Research!America
- State Patients Equal Access Coalition

## Bringing the Patient Voice to Washington

In 2015, the **Cancer Policy Institute** team informed, educated and advanced the thinking of policymakers on issues important to people touched by cancer. Priorities included comprehensive high-quality health care, access to appropriate treatments, the need to incorporate psychosocial distress screening and supportive care into clinical trial protocols and the importance of the patient voice in value, among others.



Wendy Wigger (far left) meeting with Congressman Fred Upton (far right), Congresswoman Diana DeGette (3rd from the left), and other patient advocates in Kalamazoo.



Congressman Dave Loeb sack (left) and Melissa Wright (right) at Gilda's Club Quad Cities.



## Checklist Helps Patients Shop for Care

The **Cancer Policy Institute** is proud to lead a coalition of 19 advocacy partners to deliver the *Cancer Insurance Checklist (CIC)* to people living with or at risk for cancer. The 2015 update and re-launch included English and Spanish versions of this valuable tool.

The checklist helps people make informed decisions about their health care and shop for insurance in the state insurance exchanges. Since its initial release in 2013, *CIC* has been downloaded and distributed at least 60,000 times to ensure that more people with cancer or a history of cancer have the coverage they need.

CSC would like to thank Novartis Oncology for their generous support of the *Cancer Insurance Checklist* and the partner organizations for their collaboration.

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## THANK YOU to the Cancer Policy Institute Advisory Board

The **Cancer Policy Institute** benefits from the active participation of an expert advisory board that provides substantial advice and guidance on effective cancer advocacy strategies. The advisory board members are:

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“I was recently diagnosed with cancer at age 39. I’m still in the works of getting a definite primary diagnosis but the doctors are leaning towards a rare sweat gland cancer. I have had two surgeries on my face since September and have been through such an emotional roller coaster. I came across this page during the month and saved your phone number for when I would need to call. Last night was that time. I called and spoke to Carol who was AMAZING!

She listened with a caring ear to my story and provided me with resources and phone numbers for support. She made me feel at ease when we spoke and offered encouraging words. I just wanted to say ‘Thank you’ for offering a service to people who need help! And a special THANK YOU to Carol who was simply amazing when I needed someone to talk to!”

—Amy Marchany-Brown, CSC Facebook follower

## Redefining the Cancer Experience Through **COMMUNITY**

### Breakaway from Cancer Celebrates 10 Years

For the tenth consecutive year, the Cancer Support Community was proud to be a partner of Breakaway from Cancer, a national initiative founded by Amgen Oncology in 2005. Breakaway from Cancer aims to raise awareness of the many vital resources available to people affected by cancer. In addition to CSC, this partnership includes the National Coalition for Cancer Survivorship, the Patient Advocate Foundation and the Prevent Cancer Foundation.

Together, these four groups reach millions of patients and family members through events, media coverage, internet exposure and professional meetings, ensuring that all people touched by cancer



have access to educational support services across the continuum of the cancer journey.

Highlights of the year included the Amgen Tour of California and the Dempsey Challenge in Lewiston, Maine. Held in May, the annual Amgen Tour of California is America’s largest cycling race. Thousands of patients, caregivers, family members and friends received valuable information, support and resources at the event’s Lifestyle Festival. A second athletic event brought BFC partners together again in October. Maine’s Dempsey Challenge is a run/walk/cycle fundraising experience, which includes a weekend of wellness activities to benefit the local community.

We look forward to continuing this collaboration with Amgen Oncology and the Breakaway from Cancer team for many years to come.



## Spring Celebration Honors Cancer Heroes

The Cancer Support Community's annual spring celebration celebrates heroes in the cancer community while raising vital funds to advance CSC's mission. The 2015 event introduced the "I am" campaign and featured remarks from special guest Lee Tomlinson and the presentation of four awards honoring Harold and Harriet Benjamin, founders of The Wellness Community, and Joanna Bull, founder of Gilda's Club Worldwide.

Founders Award for Spirit recipient Daniel Jacobs started boxing at 15, rising to become an alternate for the 2008 Olympic team. His 2011 diagnosis with osteosarcoma caused partial paralysis of his legs and damaged nerves in his spine. He returned to boxing after treatment, becoming the 2014 WBA middleweight champion and first cancer survivor to win a world championship in boxing.

The Founders Award for Leadership honored South Carolina's Greenville Health System Cancer Institute and its medical director, W. Larry Gluck, MD. Under Dr. Gluck's leadership, the institute established the Center for Integrative Oncology and Survivorship, featuring a first-in-the-nation partnership with CSC to offer social and emotional support in a hospital setting.

The Founders Award for Innovation celebrated the contributions of Lilly Oncology, a global leader in cancer drug development, disease management, philanthropy and volunteerism.

Accepting the Founders Award for Empowerment was Emmy Award-winning director Barak Goodman on behalf of *Ken Burns Presents Cancer: The Emperor of All Maladies*. Based on the Pulitzer Prize-winning book, this three-part PBS film series combines historical narrative, personal stories and breakthrough discoveries.

Attendees heard from special guest Lee Tomlinson, a successful executive, author and public speaker. As a stage III cancer survivor and direct recipient of *non-compassionate care*, Lee devotes his life to inspiring health care professionals to provide high-quality service to all patients, all the time.



Founders Award winner Dr. Gluck poses with his wife Diane Gluck and Diane Perlmutter.



Director Barak Goodman displays his Founders Award with host Jack Ford.



Broadway star Lindsay Mendez wowed the crowd with stunning performances throughout the evening.



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## I AM A...Campaign

Everyone has a connection to cancer, and the Cancer Support Community (CSC) is here to help. The 2015 “I am a” campaign brought this message to thousands through an awareness effort made possible by EHE International’s donation of a prominent Manhattan display window. For the month of July, a window at 10 Rockefeller Plaza highlighted CSC’s services and everyone’s connection to cancer, reaching more than 250,000 people per day. A parallel campaign encouraged people across the country to share their connection to cancer on social media.

The Rockefeller Center window featured the words, “Everyone knows someone touched by cancer. I am a...” An LCD screen displayed a scrolling list of endings to “I am a...” to reinforce the message that no one should face cancer alone. This campaign first debuted at CSC’s Spring Celebration in April where guests could pose beneath an “I am a...” sign, holding a card describing their connection to cancer. From patient to survivor to caregiver, this campaign serves as a reminder that cancer affects everyone, not just the person diagnosed, and communities of support exist for all.

CSC is grateful to EHE International for the opportunity to reach so many people who might need and not otherwise be aware of these resources.



## Team CSC: Changing the Lives of People Touched by Cancer, 1 Mile at a Time

This past fall, the Cancer Support Community partnered with Events DC Nation’s Triathlon for our 1<sup>st</sup> annual Team CSC event. The 12 triathletes on the CSC team dedicated their training, spirit and fundraising to support families affected by cancer so that no one faces cancer alone. Through their tireless efforts, Team CSC surpassed its fundraising goal, raising more than \$18,000 for CSC programs

and services, a portion of which was given to Whitman Walker Health. For information on how to join or support the 2016 Team CSC, visit [cancersupportcommunity.org/join-team-csc-2016](http://cancersupportcommunity.org/join-team-csc-2016).

Thank you to the Go Mitch Go Foundation for supporting Team CSC.

## Cancer Support Community Donor Spotlight: Joel Kent

While brainstorming over a bowl of M&M's during the founding moments of Gilda's Club Young Leadership Council (YLC) in 2006, Joel realized two very important things: cancer affects everyone in some way, and while time and money spent on medical research are critical, individuals still need social and emotional support. Whether dealing with cancer themselves or watching a family member or friend go through treatment, everyone needs a person to talk to, a place to go for information, or sometimes just a shoulder to cry on. "I remember that Gilda's Club was so connected to the human element of cancer that they consciously had a box of tissues in every room. Something as simple as that gets right to the heart of the emotional side of cancer. Tears will be shed, battles will be fought, but there is an entire support network available to those in need. The Cancer Support Community continues to drive this vision forward today, and it has been an organization that Meredith and I are honored to be connected with."

Over the years Joel has spread the message of CSC by serving on numerous benefit committees with his wife Meredith, as a member of CSC's President Council and most recently, in 2016, running the Chicago Marathon to raise awareness for CSC's mission. In 2013, Joel decided to run the Boston Marathon to benefit the Dana Farber Cancer Institute. As he embarked on his 4 months of training he thought the money raised and miles run would bring assistance and inspiration to those fighting cancer. Little did he realize that during the time of his preparation his own mother would be diagnosed with colon cancer. "Everyone, in some way, is connected to cancer. Having my mom's diagnosis coincide with the goal of trying to run 26.2 miles



minimized what I was trying to do and put the spotlight on why I was doing it." Three marathons later Joel still runs hard and supports his mother as she continues to fight her much more challenging race against cancer.

Joel and Meredith Kent have been active and vocal supporters of the Cancer Support Community mission for the past decade. In 2013 the Cancer Support Community honored Joel, along with other founding members of the YLC, with the Founders Award for Leadership. Currently, Joel is Head of Americas Credit Derivatives Trading at Credit Suisse in New York. Meredith spends much of her time raising their two wonderful children in Westchester, where she is Treasurer of both the elementary school's PTA and Westchester Reform Temple's Chapter of Women of Reform Judaism.

The Cancer Support Community would like to thank Joel and Meredith for their continued and tireless support of CSC's mission.



## Thank you to our 2015 Team CSC Athletes:

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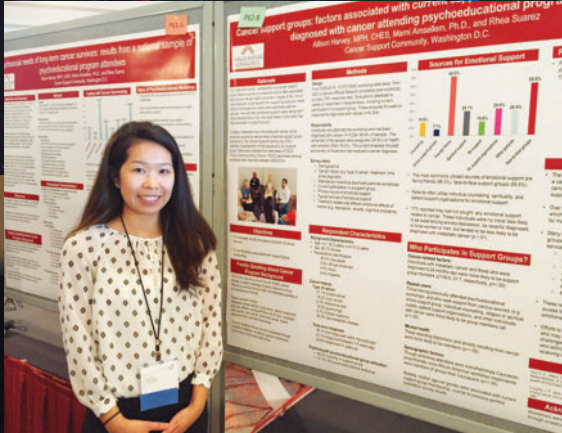
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## Ways to Give

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

### ONLINE, BY MAIL, OR BY PHONE

To make a donation online, visit our website at [www.cancersupportcommunity.org](http://www.cancersupportcommunity.org) and click on "Donate." Online gifts can be made by credit card, or you can print a form and return it by mail to:

**Cancer Support Community**  
1050 17<sup>th</sup> Street, NW, Suite 500  
Washington, D.C. 20036

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

### SHOP IN THE CANCER SUPPORT COMMUNITY'S MARKETPLACE

CSC's Marketplace offers multiple opportunities to purchase unique, one-of-a-kind items to raise funds for CSC's mission. Items include John Wind Maximal Art jewelry, customizable Bravelets, Pour le Monde perfume and more. CSC also partners with Goodsearch/GoodShop to turn ordinary online purchases into an automatic donation for CSC. Visit [www.cancersupportcommunity.org/shop-csc](http://www.cancersupportcommunity.org/shop-csc) to shop our Marketplace items and register for Goodsearch/GoodShop.

### PERSONAL FUNDRAISING

Be part of a passionate community of supporters by starting a fundraising campaign, such as running a marathon, celebrating a birthday or fundraising with your classroom. Start your campaign by visiting [cancersupportcommunity.org/how-help](http://cancersupportcommunity.org/how-help).

### VOLUNTEER

Providing support to all people touched by cancer is at the core of everything CSC does. Strong and engaged volunteers strengthen our efforts to ensure that no one faces cancer alone. For volunteer opportunities visit [cancersupportcommunity.org/how-help/volunteer](http://cancersupportcommunity.org/how-help/volunteer)

### MATCHING GIFTS

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

### TRIBUTE AND MEMORIAL GIFTS

Use any method 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.

### FEDERAL APPEALS

*(For Government Employees)*  
Federal employees will find the Cancer Support Community listed as an option in the alphabetical index of the Combined Federal Campaign (CFC). Our CFC number is 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 information.

### STOCK GIFTS

Gifts of stock can be a preferred method for some making charitable contributions. CSC provides the information for transferring stock to our account. Please call 202-659-9709 for additional information.

### 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 pickup, at no cost to you. Once your vehicle has been sold, you will be sent a receipt for your tax records, and the sale proceeds will be donated to CSC in your name. Learn more about the vehicle donation program by calling 1-877-272-5650 or visiting [cancersupportcommunity.org/ways-give](http://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. If you would like to speak with us about naming CSC as a beneficiary, please call 202-659-9709.

## 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 Gold Participant distinction in 2015. This is the highest level of participation that a non-profit 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 the highest, 4-star rating by Charity Navigator. This designation is administered based on the combination of the programs and services offered and the way in which organizations function financially.



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



The Cancer Support Community was honored to be named as a Top Nonprofit Organization by Philanthropedia. This designation was assigned following 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.

# Financial Report

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

## Consolidated Statement of Activities

Statement of Activities, year ended December 31, 2015

	UNRESTRICTED	TEMPORARILY RESTRICTED	PERMANENTLY RESTRICTED	TOTAL
<b>REVENUES AND OTHER SUPPORT</b>				
Development Income	\$ 610,137	—	—	\$ 610,137
Interest Income	64,066	—	—	64,066
Unrealized Loss of Investments	(116,483)	—	—	(116,483)
Service Delivery				
Program	591,350	693,421	—	1,284,771
Research and Training	334,277	1,267,316	—	1,601,593
Events and Special Initiatives	729,020	—	—	729,020
Less Direct Expenses	(197,383)	—	—	(197,383)
Education/Outreach	510,709	870,809	—	1,381,518
Policy/Advocacy	284,533	972,527	—	1,426,552
Affiliate Activities	746,553	—	—	746,553
Communications	50,000	—	—	50,000
In-Kind Revenue	98,580	—	—	98,580
Miscellaneous Income	66,331	—	—	66,331
PPS Sales, Net of Direct Costs of \$22,378	247,455	—	—	247,455
Net Assets Released from Restriction	5,212,010	(5,212,010)	—	—
<b>Total Revenues and Support</b>	<b>\$ 9,231,155</b>	<b>\$ (1,407,937)</b>	<b>—</b>	<b>\$ 7,823,218</b>

### EXPENSES

Program Services	\$ 6,006,349	—	—	\$ 6,006,349
Management and General	402,788	—	—	402,788
Fundraising	326,545	—	—	326,545
Operating Expenses: PPS	315,203	—	—	315,203
<b>Total Expenses</b>	<b>\$ 7,050,885</b>	<b>—</b>	<b>—</b>	<b>\$ 7,050,885</b>

Change in Net Assets	\$ 2,180,270	\$ (1,407,937)	—	\$ 772,333
Net Assets at Beginning of Year	\$ 1,962,077	\$ 6,759,719	\$ 10,000	\$ 8,731,796
Net Assets at End of Year	\$ 4,142,347	\$ 5,351,782	\$ 10,000	\$ 9,504,129

### EXPENSES

**PROGRAMS  
AND  
SERVICES  
85%**

**MANAGEMENT  
AND GENERAL  
6%**

**FUNDRAISING  
5%**

**PATIENT PLANNING  
SERVICES 4%**

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.

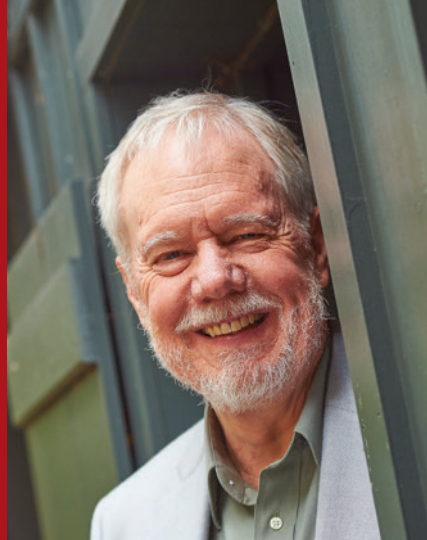
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