





## THE POWER OF OUR COMMUNITY

The patient experience is at the heart of everything we do. From our worldwide network of affiliates, hospitals, and health care centers to our cutting-edge research and advocacy on the federal, state, and local level, we strive to ensure that people impacted by cancer can live their lives to the fullest. By giving voice to our members' needs, we provide the support services, education, and representation they deserve so that no one faces cancer alone.

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## LETTER FROM OUR LEADERSHIP

#### Dear Friends of the Cancer Support Community:

It is our honor to share with you the story of a thriving organization that is adopting innovative practices and impacting the lives of more people than ever—all thanks to your steadfast support.

Your generosity and commitment enabled us to touch the lives of more than one million individuals and provide \$50 million in free services in 2017 alone.

Behind each number is a story—the patient struggling with how to tell her kids about her diagnosis, the caregiver keeping up a strong front who needs a shoulder to cry on, or even the friend who volunteered to research solutions for a family facing financial struggles due to cancer-related costs.

Whether these individuals received support walking into one of our more than 170 service locations, calling our free helpline, or searching our education resources online, they gained a sense of control during what can be a chaotic time.

In addition to providing these free services, we were invited to testify before Congress and also released a groundbreaking research report documenting the experience of thousands of patients.

Whether we are on Capitol Hill or at one of the many leading medical conferences releasing research findings—one principle unites all of our work: Cancer is a disease that no one can, or should, face alone.

While we have witnessed many significant advances in treating this devastating disease, nothing takes the place of the power, inspiration, companionship, and connection that comes from community.

The strength of our community runs deep.

Thank you for taking a look back at what we intend to achieve as we leap forward and show that community is stronger than cancer.

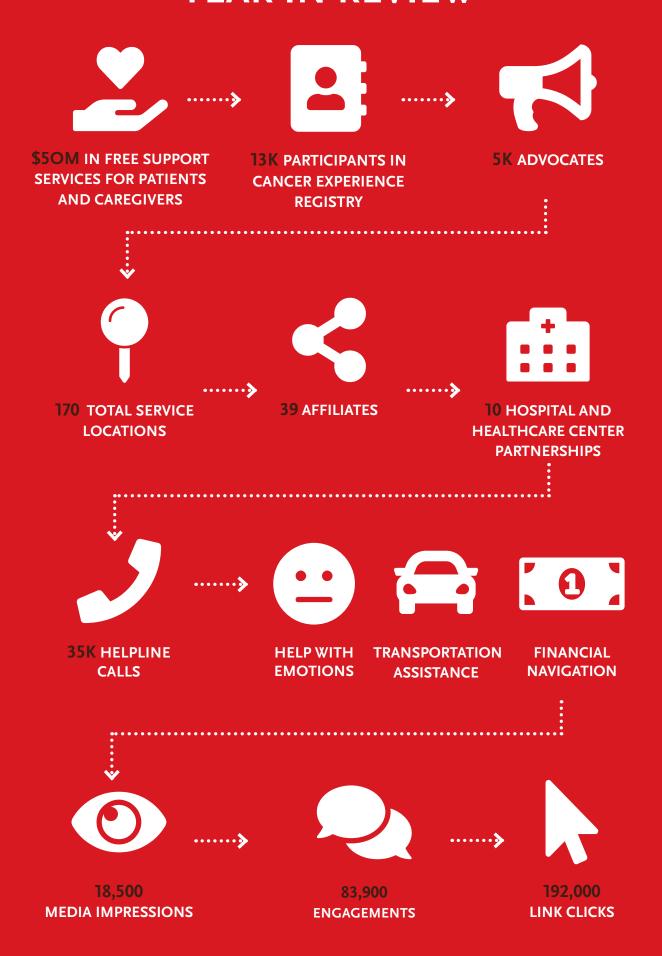


Kim Thiboldeaux
Chief Executive Officer

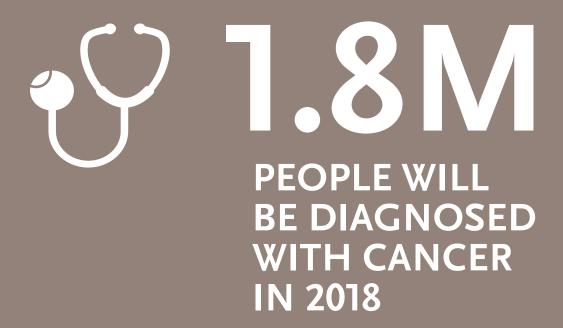


Jill Durovsik
Board Chair

#### **YEAR IN REVIEW**



## DOCUMENTING THE EXPERIENCE



# RESEARCH & TRAINING INSTITUTE

#### **EVERY DATA POINT TELLS A STORY**

Close to 1.8 million individuals will be diagnosed with cancer in 2018. And each of them, along with their families and caregivers, will have their own stories and travel a different path.

Since 2008, our Research and Training Institute has been rigorously examining the patient experience—documenting the "real-life" emotional and social concerns of people facing cancer in real time—and sharing our findings with health care providers and stakeholders in the broader cancer community to inform policy and program decision-making.

By identifying, clarifying, and elevating the issues that matter most to the people we serve, the Cancer Support Community redefines what it means to deliver truly patient-centered care from diagnosis through treatment and beyond.

## ONLINE COMMUNITY



13K
SURVIVORS,
PATIENTS, AND
CAREGIVERS

## CANCER EXPERIENCE REGISTRY

A unique resource for policymakers, health care providers, advocates and, most importantly, patients, the Research and Training Institute's Cancer Experience Registry puts the patient experience front and center. It captures and amplifies patients' voices to ensure they are heard, understood, and given access to treatments that yield better outcomes and improved quality of life. Registry insights are shared broadly at medical and scientific conferences throughout the country and are used to inform policy and best practices.

As of today, over 13,000 participants—survivors, patients, and caregivers—representing over 45 cancer types have joined the Registry. We are committed to expanding that number and growing our influence this year and beyond.

In the past year, we added an innovative screening and referral tool to the Registry that is designed to measure the benefits, stresses, and costs of caregiving. The initiative, **CancerSupportSource—Caregivers**, will drive the development of evidence-based programs to support the friends, families, and loved ones of cancer patients and survivors.



"I was diagnosed in January of 2005. During the process I was blessed with help and prayers from family, friends and co-workers. Realizing how blessed I am, I took up advocacy. ..... and recently the CSC Greater Philadelphia. All worthy and active communities helping others through this trying journey."

-Lou Lanza

"I was a Breast Cancer survivor for 10 years before reoccurrence, but had never heard about CSC until your social worker came to educate us about CSC and metastatic cancer at my church. I attend the MBC group as often as my energy and schedule allows. It helps to be with others going through this journey. I have enjoyed yoga, the luncheons and especially the art class. It's crucial to have a home away from home where everyone understands and doesn't need you to explain."



been successful without CSC and my 'diamonds'. Throughout Breast Cancer, I was able to rely on CSC for support, education and friendships, I always recommend CSC to other newly diagnosed individuals as a wonderful resource as well as a place to find comfort. I wore my mother's diamonds to my chemo sessions keeping her close to me. (She passed away from pancreatic cancer when I was young.) Who knew that I would inspire other women who are diagnosed with cancer? As my journey continued, I sent out emails to friends for updates, which turned into a blog and now a book."

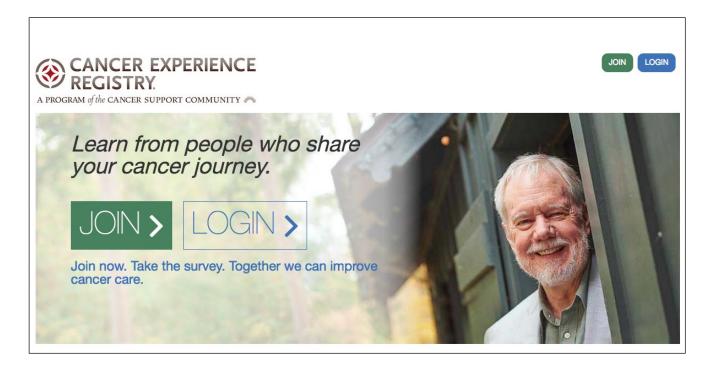
"My cancer journey has (naturally) been long and tedious, but forces one to put life in perspective; you learn the true meaning behind taking one day at a time...my favorite quote is one by Helen Keller: 'Keep your face to the sunshine and you cannot see the shadow.'"

## VALUED OUTCOMES IN THE CANCER EXPERIENCE

#### Giving voice to what matters



Understanding what matters to people with cancer has long been a part of the CSC mission. We laid the groundwork for a comprehensive study to measure how cancer patients define value in health care. In order to create and scientifically validate the Valued Outcomes in the Cancer Experience (VOICE) Measure, we have surveyed hundreds of patients to determine what they deem important and what brings them hope as they face their illness and treatment. Still in development, this initiative expected to launch within the next year and is a joint project of the Research and Training Institute and the Cancer Policy Institute.



"The great thing about the Cancer Experience Registry is that it really gives substance to the patient voice. For decades, we as providers have thought we knew what our patients were thinking, but the Registry has turned that around. We are learning things that we never anticipated that gives our patients more power and our health care providers better tools."

-Craig Cole, MD, University of Michigan; Member of the Cancer Experience Registry Advisory Council

#### WHAT PATIENTS ARE SAYING



39% OF CANCER
SURVIVORS RATE THEIR
OVERALL HEALTH AS VERY
GOOD OR EXCELLENT



53% ARE WORRIED
ABOUT THE FUTURE
AND WHAT LIES AHEAD



47% ARE AT RISK FOR CLINICAL DEPRESSION



93% RATED QUALITY OF LIFE AS A VERY IMPORTANT FACTOR WHEN WEIGHING TREATMENT OPTIONS



24% DO NOT FEEL PREPARED TO DISCUSS TREATMENT OPTIONS WITH THEIR DOCTOR



45% DECIDE
ON TREATMENT
TOGETHER WITH
THEIR CARE TEAM



1 IN 5 REPORTED THAT THE HEALTHCARE TEAM DID NOT EXPLAIN SHORT-TERM SIDE EFFECTS



52% SAID THEY
RECEIVED GUIDANCE
ON LONG TERM SIDEEFFECTS OF TREATMENT



14% DID NOT TELL
THE CARE TEAM
ABOUT SIDE EFFECTS
AND SYMPTOMS



43% THOUGHT LACK OF TRANSPORTATION WOULD STOP THEM FROM PARTICIPATING IN A CLINICAL TRIAL



77% BELIEVED THAT INSURANCE WOULD NOT COVER CLINICAL TRIAL COSTS



76% FEAR RECEIVING A PLACEBO IN A CANCER CLINICAL TRIAL



MORE THAN 1 IN 10 POSTPONED FILLING PRESCRIPTIONS TO REDUCE COSTS



73% DID NOT TALK ABOUT COSTS OF TREATMENT WITH A MEMBER OF THE CARE TEAM

Source: Cancer Experience Registry



30% DEPLETED THEIR SAVINGS BECAUSE OF TREATMENT COSTS

## ADVOCACY AND IMPACT



5K

ADVOCATES:
PATIENTS,
CAREGIVERS,
SURVIVORS,
AND HEALTH
CARE PROVIDERS

# CANCER POLICY INSTITUTE

#### ADVOCATING FOR PATIENTS AND CAREGIVERS

Our Cancer Policy Institute works alongside patients as partners in advocacy. We work together to educate federal, state, and local policy and decision makers on the physical, emotional, social, and financial challenges patients experience over the course of their illness and beyond.

In collaboration with the Research and Training Institute and our extensive affiliate network, we utilize evidence-based research to advocate for policies and regulations that are centered around the patient. We are working towards a future where cancer patients and survivors can have access to comprehensive, high-quality, timely, and affordable medical, social, and emotional care.

## THE CANCER MOONSHOT: ONE YEAR LATER

On June 27, 2017, CSC held a daylong summit to mark the one-year anniversary of the Biden Cancer Moonshot—celebrating its progress and articulating an action plan for the future.

CSC co-hosted this event with six cancer patient advocacy organizations: American Cancer Society Cancer Action Network; Cancer Care; Friends of Cancer Research; LIVESTRONG Foundation; National Coalition for Cancer Survivorship, and the National Patient Advocate Foundation.

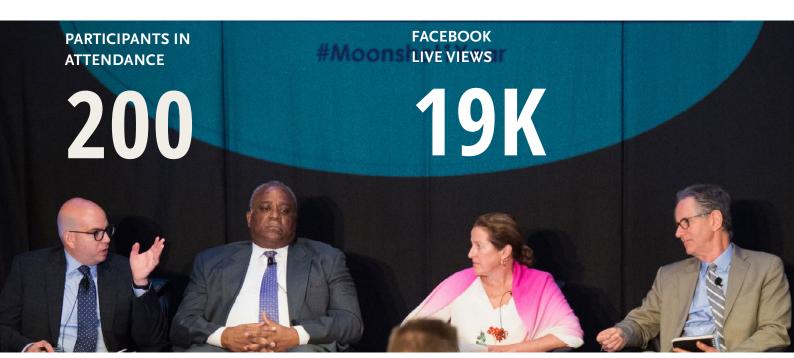
Participants heard from a variety of speakers including Greg Simon, President of Biden Cancer Initiative; Chris Draft, former NFL

player and founder of The Chris Draft Family Foundation, relating his experience in caring for his wife, who passed away from lung cancer, and Dr. Douglas Lowy and Dr. Elizabeth Jaffee, Dr. Ramy Ibrahim, Vice President, Clinical Development, Parker Institute for Cancer Immunotherapy, who highlighted progress made toward the Government's Blue Ribbon Panel Recommendations and the evolving role of the National Cancer Institute.

Panel discussions included improving cancer clinical trials, eliminating disparities in cancer care, opportunities through data sharing, and preventing cancer.

### "In just a year and a half, the world of cancer has gone through a seismic shift."

-Kim Thiboldeaux, President and CEO of CSC



#### ADVOCACY ON THE HILL







## MEDICAL PRODUCT MANUFACTURER COMMUNICATIONS

For the past two years, the CPI has been meeting with policymakers and other stakeholders to discuss the communication of offlabel information and the impact on patients. These conversations generated an informal coalition and increased the CPI's interactions and communications with the House Energy and Commerce Committee. On July 12, CSC president Linda House was invited to testify before the Energy and Commerce Committee (Subcommittee on Health) on "Examining Medical Product Manufacturer Communications," where she urged greater patient access to comprehensive medical information "vital to planning care for and improving outcomes for patients and elevating the patient voice."

#### PATIENT EXPERIENCE AND RESEARCH ACT (PERA)

The CPI continued to advocate for patient protection and patient-centered legislation with its support of a bipartisan bill, H.R. 2244, "Patient Experience in Research Act of 2017" (PERA). The legislation will change how the patient experience is measured in clinical research and supports a "voluntary pilot project to evaluate the social and emotional distress experienced by patients participating in a clinical trial of a drug or biological product that is intended to treat a serious or life-threatening disease or condition."

## FDA REAUTHORIZATION ACT OF 2017 (FDARA)

CSC worked closely with Congress and the FDA to revise the definition of "patient experience data" to include not only physical, but also psychosocial impacts of a "condition, therapy, or clinical investigation." This is the first statutory acknowledgement of the need to include psychosocial impacts as equally important components of the patient experience.

### IN GRATITUDE



84¢ per dollar

GOES TO SERVICES FOR PATIENTS AND FAMILIES

# MEET OUR DONORS & MEMBERS

Our work is made possible by the generosity of our valued contributors.

To learn how you can support CSC, visit <a href="https://www.cancersupportcommunity.org/make-difference">www.cancersupportcommunity.org/make-difference</a>.

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## STRENGTHENING OUR AFFILIATE COMMUNITY



## AFFILIATES AND EDUCATION

Along with advocacy and research, CSC's Affiliate Network and Education division support patients and their loved ones with counseling services, financial navigation, health and wellness programs, and educational resources to help them cope with their disease—from understanding their diagnosis and treatment options to talking to their children or budgeting for care. Our goal is to provide the right tools at the right time in the right form to make a positive difference in their lives and empower informed decision-making.

#### AFFILIATE HIGHLIGHTS



## LEADERSHIP CONFERENCE

The 2017 Affiliate Leadership Conference took place in Washington, D.C. from November 15-17 and welcomed 115 affiliate leaders to hear from experts in the field, share best practices, and network. Among the many speakers were fundraising expert Penelope Burk and former NFL player and cancer advocate, Chris Draft.

#### **OUR AFFILIATE REACH**

72,013

TOTAL PEOPLE SERVED
AT OUR AFFILIATE LOCATIONS

72,190

TOTAL NUMBER OF PROGRAMS OFFERED BY AFFILIATES

476,536

TOTAL VISITS TO AFFILIATES





## TEAM CSC AT THE NATION'S TRIATHLON



AMY POWER BRIAN SMITH AMY POWER AND LIBBY MULLIN

#### **HOME TEAM ADVANTAGE**

Two of our incredible athletes, Brian Smith and Amy Power, have turned Team CSC into a family affair! Amy competed in the full Olympic Triathlon for Team CSC last year and helped raise vital funds for those affected by cancer. This year, Amy is back with Team CSC and she brought along her husband Brian to compete as well.

Aside from going on regular bike rides together, they have participated in multiple relay triathlons this summer with their twin daughters, Samantha and Emily. Recently, Brian and Samantha won the co-ed relay and Amy and Emily won the female only relay at the Luray Triathlon in Virginia.

**OVER 3 YEARS THE RACE RAISED** 



### I am dedicating my Tri to my dad, Fred Bohannon—whose brave journey with acute myeloid leukemia inspired so many.

-Linda House, President, CSC





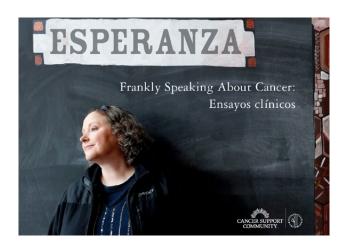


LINDA HOUSE ELIZABETH FRANKLIN RANDY CROOKS

The Nation's Triathlon not only gave us the opportunity to participate in an elite and fun athletic competition but gave team members a unique bonding experience in support of **CSC**.

-Elizabeth Franklin, Executive Director, CPI and 2017 Tri Cyclist

#### **EDUCATION**



#### **ACCESSIBLE MATERIALS**

A major focus of the past year was to expand our reach with more culturally diverse and accessible educational offerings, starting with the translation and redesign of our Frankly Speaking About Cancer: Clinical Trials into Spanish. These materials join our growing library of multi-lingual resources on a variety of cancer types and topics.

The new Spanish-language photo narrative provides easy-to-understand information and relatable imagery to help patients and their families take advantage of clinical trials. Focus group research found that "Esperanza" successfully communicated how medical advances take place, the importance of being an informed health care consumer, and the value of having Latino individuals participate in clinical trials.

75,600
FRANKLY SPEAKING
PUBLICATIONS DELIVERED

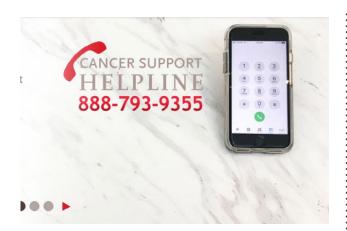


#### COURAGE, COMFORT, AND CARE: WebMD AND ROBIN ROBERTS

CSC CEO Kim Thiboldeaux appeared in this sixpart video series on the challenges, treatments and management of cancer hosted by breastcancer survivor Robin Roberts.

**7K** 

ATTENDEES TO 68 WORKSHOPS AND WEBINARS



#### CANCER SUPPORT HELPLINE

The Cancer Support Community's Helpline is staffed by professional counselors and oncology resource specialists who are experienced in helping people with cancer and their caregivers. The counselors provide emotional support as well as information about living with cancer and referrals to local, regional, and national resources.

"Please let everyone know how very thankful we are from the bottom of our hearts! I was so upset the day I called for help but you understood my pain. Cancer hits everyone, the family too. We will never forget the kindness and help. Thank you so much for helping us. God bless each and every one of you"

Cancer Support Helpline caller

200+

LANGUAGES AVAILABLE
WHEN YOU CALL THE HELPLINE



#### THE PROMISE OF BIOSIMILARS

Biosimilars are an exciting new supportive treatment for patients undergoing chemotherapy. CSC CEO Kim Thiboldeaux spoke with Dr. Leah Christl, Associate Director for Therapeutic Biologics in the FDA's Center for Drug Evaluation and Research (Office of New Drugs) about their development and promise.

The interview appeared on the "Frankly Speaking About Cancer" radio show, a weekly broadcast empowering listeners to live well with cancer.

#### **TOP 5 RADIO SHOWS FOR 2017**

A Chef with No Stomach-A conversation with Hans Rueffert

The Importance of Clinical Trial Participation

Understanding Professional Grief

Lifting the Fog of Chemo Brain

Patient Perspectives: Cancer Clinical Trials

168K+

REGULAR RADIO LISTENERS IN OVER 24 COUNTRIES

## A NEW PARADIGM



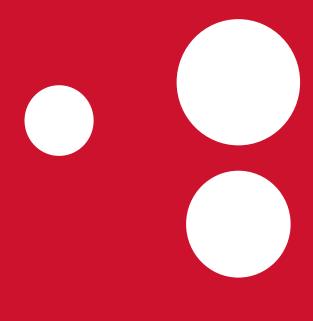
DEDICATED TO DEVELOPING TOOLS, EDUCATION, AND SERVICES

## GOING FORWARD

"The emperor of all maladies," as physician-author Siddhartha Mukherjee described it in his "biography of cancer," has met its match. Breakthroughs in the treatment and management of this ancient disease have given patients and their families new hope. And all of us at the Cancer Support Community are dedicated to developing and giving them the tools, education and services they need to make their way through this changing and challenging time.

In the past year, we've evolved many of our programs and platforms to reach a broader, more diverse population and increased awareness and impact of our thought-leadership and advocacy among our stakeholders.

## STRATEGIC INITIATIVES



#### **IMMUNOTHERAPY & ME**

In September, we introduced Immunotherapy & Me, the first-of-its-kind educational and support program designed to help both patients and providers identify and manage immunotherapy-treatment symptoms and side effects. The pilot program was launched in partnership with nine highly regarded oncology centers around the country, including Catholic Health Initiatives (Washington state), Centura Health (Colorado), OHC (Ohio), Rosewell Park Cancer Institute (New York) and West Cancer Center (Tennessee and Mississippi).

#### A HEALING SPACE

Early in 2017, The Barbara Bradley Baekgaard Family Foundation pledged more than **\$500,000** to support the development of homelike and welcoming spaces in hospitals where cancer support groups and programs are held. It is believed that a well-designed environment can have a positive therapeutic effect on patient satisfaction and can lead to reduced health care costs and improved patient outcomes.

**PARTNERSHIPS WITH** 

9

**ONCOLOGY CENTERS** 

\$500,000

PLEDGE FOR HOMELIKE SPACES IN HOSPITALS

## DIGITAL STRATEGY

#### **MY LIFELINE**

Twenty one years ago, Marcia Donziger was diagnosed with ovarian cancer at the age of 27. She was overwhelmed by the relentless obligation to communicate with her caring friends and family throughout her treatment process. When her friend, Lori, was diagnosed with brain cancer years later, Lori's friends created a beautiful website which simplified the communication process. When Lori passed away at age 35, Marcia could not stop thinking about her impact in the world, and inspiration struck. In memory of Lori, Marcia felt compelled to create a non-profit organization with the mission to transform the cancer experience through community and connection. Eleven years ago, MyLifeLine.org was born with the mission to foster connection, inspiration, and healing.

With MyLifeLine, patients can set up a private, personalized online community where the patient owns the data shared; access cancerspecific resources to provide vital education and knowledge; utilize a helping calendar to organize practical support like rides to the doctor; raise funds for expenses not covered by insurance; and invite close friends and loved ones to connect and engage during the recovery process.

MyLifeLine merged with CSC in January 2018 and now serves 37,000 active users. Along with CSC's legacy online and phone support services, the goal for our merger is to expand our patient-centered services in a ground-breaking, innovative way. Our vision is to create a multimedia digital channel—

accessible to all-full of uplifting, inspirational content that encourages a strong focus on health and wellness for the whole community.

MyLifeLine ACTIVE USERS

37,000

"Cancer breeds stress, anxiety and isolation. MyLifeLine.org exists to counteract the devastation with hope, optimism and inspiration."

-Marcia Donziger, MLL creator and CSC, VP Digital Strategy and Business Development

"Thank you for MyLifeLine. It has truly been a blessing to us as my husband continues to struggle for his life after a stem-cell transplant a year and a half ago."

-MyLifeLine member since June 2016

#### Underwriting

MyLifeLine gratefully acknowledges the support of these underwriters: Genentech, Eisai, Astellas, Takeda, Helsinn, Boehringer Ingelheim, Pfizer, Tesaro, and Genomic.



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William Levin, MD
Paula Malone, PhD
James Metz, MD
Anne O'Malley
Patricia Robinson, MD

## 2017 FINANCIALS



## SUMMARY OF FINANCIAL RESULTS

We are humbled each and every day by the many individuals, corporate partners, and foundations that choose to invest their hard-earned resources in our work. Through them and our growing community of affiliates and partnerships, we are able to extend our reach well beyond our headquarters and balance sheet—serving as the engine behind a network that collectively delivers \$50 million in free services to people with cancer and their loved ones.

## FINANCIAL SUMMARY

For the year ending December 31, 2017	Unrestricted	Temporarily Restricted
REVENUES AND OTHER SUPPORT		
Development Income	444,906	-
Interest Income	105,375	-
Unrealized Gain of Investments	167,569	-
Service Delivery:		
Program	111,557	1,488,038
Research and Training	527,106	779,020
Events and Special Initiatives	977,527	518,184
Less Direct Expenses	(484,140)	-
Digital Services and Web	-	120,000
Education/Outreach	84,662	1,613,969
Policy/Advocacy	1,132,844	560,306
Special Purpose Funds	24,919	-
Affiliate Activities	502,855	-
Communications	17,500	-
In-kind Revenue	83,767	-
Miscellaneous Revenue	99,563	
PPS sales, net of direct costs of \$192,600*	5,096	-
Net Assets Released from Restriction	2,291,819	(2,291,819)
Total Revenues and Support	6,092,925	2,787,698
EXPENSES		
Program Services	6,772,401	-
Management and General	513,944	-
Fundraising	509,792	-
Operating Expenses: PPS	413,272	-
Total Expenses	8,209,409	-
Change in Net Assets	(2,116,484)	2,787,698
Net Assets at Beginning of Year	3,473,561	6,165,242
Net Assets at End of Year	1,357,077	8,952,940

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

Permanently	Total	
Restricted		
-	444,906	
-	105,375	
-	167,569	
-		
-	1,599,595	
-	1,306,126	
-	1,495,711	
-	(484,140)	
-	120,000	
-	1,698,631	
-	1,693,150	
-	24,919	
-	502,855	
-	17,500	
-	83,767	
-	99,563	
_	5,096	
	,	
-	-	
-	8,880,623	
	6,772,401	
	513,944	
	509,792	
	413,272	
	8,209,409	
-	671,214	
10,000	9,648,803	
	10,320,017	
10,000	10,320,017	

"Cancer is a costly disease emotionally and financially and places unimaginable stresses on patients and their families. Thanks to our donors and underwriters, we are able to fund programs that make their lives a little bit easier. And less isolating. So that no one faces cancer alone."

–Jeff Travers, Chief Operating Officer

WE ARE HONORED TO RECEIVE THE HIGHEST RATINGS BY GUIDESTAR, USA; CHARITY NAVIGATOR; INDEPENDENT CHARITIES AND PHILANTHROPEDIA.









"It has been wonderful to be able to connect with other folks like myself. When my cancer returned and I was hit with an 'incurable diagnosis', I felt so alone. Five years later, I'm still thriving. Every day is a gift!"

-Diana DeSantis

"CSC has been my road to recovery. This place is like a 'diamond in the rough'. I have met so many wonderful people here. It has really helped me to find the 'New Me'!"

-Gloria Odom



during my own personal journey while giving so much to so many cancer patients and survivors in the community. What I thought would be one of the worst years of my life, turned out to be one of the best due to the outpouring of love and support from all of my doctors, family, friends, and community."

"It's wonderful to be able to share with people who are going through the same journey as me."

-Leslie Robinson



#### **CANCER SUPPORT COMMUNITY**

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